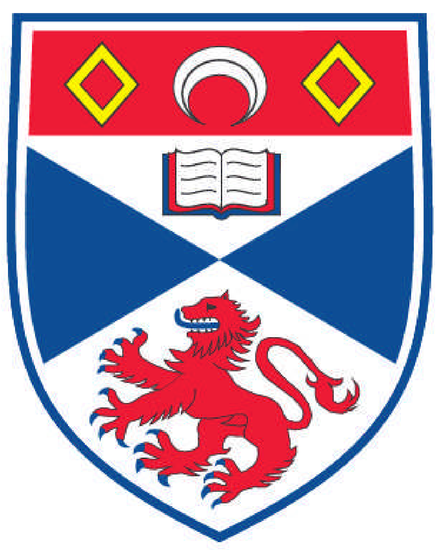
HEALTH PROFESSIONALS AND ETHNIC PAKISTANIS IN BRITAIN : RISK, THALASSAEMIA AND AUDIT CULTURE

Richard Murphy

A Thesis Submitted for the Degree of PhD
at the
University of St. Andrews



2005

Health Professionals and Ethnic Pakistanis in Britain: Risk, Thalassaemia and Audit Culture.

By

Richard Murphy MA BA (Hons.)

Thesis presented for degree of PhD

University of St Andrews

February 2005

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ACKNOWLEDGEMENTS

I would first like to thank my wife Penny for all of her help, support and encouragement during this research – without you I could never have finished. Thank you Katey, Scott, Adam and Jake for going without to allow me time to carry out the research and write this thesis. Thank you to Arif for all his help, ranging from teaching me how to eat a Pakistani mango correctly to giving me Roupes enough to survive my arrival in a strange land, and also for the gift of his copy of the Qur'an. To Khalid, Nabila and family both here and in Lahore for showing me the true meaning of 'family' within the Pakistani community. To Salma and family without whom I could not have gained such broad access to the community in England. To Dr M for the air ticket and medical kit that allowed me to do the work in Pakistan. To Margaretha and her team for their patience in explaining both the 'science' and the 'humanity' of thalassaemia to me. To Kalum who assisted me in meeting members of the community in Scotland. Finally, my thanks also go to all of the many others (too many to mention individually) who have given of their time, and patience, over the past five years, both within the Pakistani community and also the NHS – without you all I would have had nothing to write. I would also like to thank my supervisors, David and Alex, who have supported and encouraged me throughout my time at St Andrews. The ESRC without whose economic support my family and I would have starved during the process of this research. The Department of Social Anthropology and the Access Fund, at University of Durham, also made an economic contribution to the field trip to Pakistan. Virginia, whom I have never met, but who let me use her flat during my stay in Lahore. Beth, for her diligence in proofreading. Finally, the Department of Social Anthropology, at St Andrews, both post grads and tutors, who firstly allowed me to join their 'family' and then supported me with constructive criticism of my work and then suggestions for moving forward. I would like especially to thank Tony and the post grads who attended the writing up seminars – you allowed me to think outside the box. This said, any mistakes made within this document are all my own responsibility. The 'science' content is to the best of my knowledge accurate, but if any reader is in doubt I would advise consulting either a learned text (there are many listed in the bibliography) or consulting a professional.

ABSTRACT

The central theme or 'red-thread' that I consider in this thesis is the concept of *risk* as it is perceived by and affects the two sides of the medical encounter – in this instance ethnic Pakistanis and Health Professionals – in Britain. Each side very often perceives risk quite distinctively, relating to the balance between the spiritual and temporal realms. This is particularly germane in matters to do with possible congenital defects within the prenatal realm for the ethnic Pakistani, and predominantly Muslim, side of this encounter. Thus one of the factors considered in this thesis is how senses of Islam impact upon the two sides. By ethnic Pakistanis Islam is seen as central to all life decisions, whilst Health Professionals view Islam with some considerable trepidation, little understanding it or its centrality to the former's decision-making processes. This is particularly significant with regard to attitudes to health and health care. In the initial stages of the project I had thought first cousin marriage (FCM), seen by ethnic Pakistanis as desirable and by Health Professionals as putting ethnic Pakistanis *at-risk,* to be central to the argument, but concluded that concerns around FCM were a 'red herring', merely a trope for the tensions between the two sides – at once both British and at-risk from *audit culture.* Although no longer central, FCM remains a viable touchstone in consideration of the two sides' perceptions of *genetic risk.* In this thesis the medical encounter between ethnic Pakistanis and Health Professionals is performed within the realm of the so called New Genetics. Here the respective understandings of the New Genetics are informed by the enculturation processes that shape the two sides' world view. Furthermore, I will agree with Lord Robert Winston's and others' concern that any attempt to eradicate an adaptive genetic mutation, in this instance, thalassaemia, from the gene pool is not only undesirable in the short term, but also that such eradications may have an adverse, and far reaching, effect on whole population groups in the future. The main thrust of my argument is that audit culture not only compounds risk for both sides, but also perpetuates *institutional racism* within the National Health Service (NHS), by promulgating what I have called the *language myth.* That is to say that much institutional racism is the unwanted by-product of the NHS's attempts to become more *patient centred* and its continuing efforts to develop systems of *best practice*. This *professionalisation* process within the NHS can be seen to impact most strongly in relation to communication - particularly the claimed *language barrier* between the two sides. This 'barrier' has worrying policy implications for any meaningful communication between the two sides, notably relating to obtaining informed consent from ethnic Pakistani patients – with a resultant increase in risk for the two sides and clear economic consequences for the NHS.

Some abbreviations used within the thesis:

CD	Community Development
CG	Clinical Geneticist
CVS	Chorionic Villus Sampling
EP	Ethnic Pakistani
GC	Genetic Counsellor
GP	General Practitioner
GSM	Genetic Specialist Midwife/Midwives
HP	Health Professional(s)
NHS	National Health Service
NSPFTH	National Screening Program For The Haemoglobinopathies
PBUH	Peace be upon Him (Islamic phrase used after the mention of a Prophet in a conversation.)
UKTS	United Kingdom Thalassaemia Society

Glossary of Urdu and Arabic Terms used:

Ashraf	Noble
Baithak	Sitting room for men
Biradari	A complex and oft changing concept, Shaw defines it as 'relatives, patrilineage' (Shaw 2000, 311). It can also mean brotherhood or give an indication of shared *zat*. In the UK the concept is also often used as a pragmatic 'catch-all' to legitimate marriages which might otherwise be problematic. Alavi (cited in Shaw 2000, 140) suggests that '*...biradari* [has] two constituent principles, descent and ties between contemporaries...'
Fatwa	A ruling on a point of Islamic [Shari'a] law given by a recognised authority.
Izzat	Respect or social standing.
Kammi	Artisan *zat*
Khun	Blood
Inshallah	If God [Allah] wills it
Lena Dena	Taking giving (Werbner 1990, 131-2). In many ways similar to Potlatch among North American Indians. Each attempts to 'out-do' the other – a form of power relationship.
Mithai	Sweets given on the birth of a child.
Purdah	Segregation via sex. Literal meaning: curtain or screen.
Zamindar	Landowning [allowed to own land] *zat*
Zat	Very similar to the Indian caste, in a system without 'untouchables' or a religious caste.

CONTENTS

INTRODUCTION

Themes:

When I began my odyssey what seems almost a lifetime ago my aims were somewhat different from those evidenced by the outcome of this thesis. The question, '*Why this subject?*', can be firmly placed at the door of serendipity. In a previous *karma* I taught in a Further Education college in the North of England. One of the courses I tutored was an RSA[1] course in Community Development which was run by the Borough Council and validated by the college for which I worked. The majority of the students were ethnic Pakistani women who lived within the catchment area. As I taught this course several things struck me as distinctive with regard to this group. I was aware of 'racism', after all I taught sociology, but this did not prepare me for the more subtle discrimination apparently being suffered by these women with regard to access to health - they suffered discrimination on the grounds of their ethnic origin. As I began to learn more of these women's lives, I decided that there were issues and debates to which I felt I could make a contribution.

I became aware that commentators claimed connection between high levels of congenital birth defects and the practice of first cousin marriage (FCM), among ethnic Pakistani families resident in the UK (Bittles 1993, 1998; Weatherall 1998). As the research progressed I also became aware that this link was contested by other commentators. Perhaps Illich's (1995) thesis of *iatrogenesis*[2] offered some clue in my attempt to open up this apparent tension? For example, Ahmad (1994, 1996) argues the attitudes of primary care workers may, by their action/inaction, be a causal factor (see also Proctor & Smith 1992, 76-80) in the reported high levels of congenital[3] defects within this particular ethnic group.

I came across 'New Genetics'[4] in relation to this tension. This concerns scientific intervention in relation to genetic traits and I guess, as for many people of my generation,

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[1] The Royal Society for the Encouragement of Arts, Manufactures & Commerce

[2] Doctor related illness. (See Illich 1995, 39-48; Porter 1997, 687)

[3] Congenital malformations, deformities, diseases etc. are those which are either present at birth, or which, being transmitted directly from the parents, show themselves soon after birth.

[4] This term refers to the rapid evolution of the technologies used to map and understand the genome. What was once a complex, painstaking and difficult task has become almost simple.

my interest in this subject stems from science fiction. The first book I read which looked at the topic of genetic engineering would have to be Heinlein's *Friday* (Heinlein 1982). Perhaps the most notable film example of the genre is Scott's *Blade Runner*[5] (Scott 1991) and a television example would be *Dark Angel*[6]. All are variations on Mary Shelley's *Frankenstein* theme, but brought forward in time to address public fascination and concern with the artificial manipulation of the human genome and the implications for the rest of humanity. In *Dark Angel* we are presented with '... a future not too far from now...' alongside the concept of trans-genic humans whose DNA has been mixed with that from other animals' genetic traits - thus building a race of 'supermen' (though Max is in fact a heroine). Herein lay a concern of many, the potential link with genetics and its bastard cousin eugenics. All of this was science fiction when I was young, yet recently Lord Professor Robert Winston talked of trans-genics as fact (University of St Andrews: 2003).[7]

The genetics relevant to this thesis concern an adaptive Mendelian recessive gene mutation common among South Asian peoples which, in the form of thalassaemia, can have a profound affect on the lives of carriers. Thalassaemia is a rare blood disorder which in its most deleterious form β (beta) thalassaemia major, is fatal if not treated. There are at any one time around 600 cases of beta thalassaemia major in Britain (UKTS 2003). The adaptive mutation, in its recessive state, provides protection for new born babies from malaria. The tension between ethnic Pakistanis and Health Professionals discussed in this thesis arises when those with the adaptive mutation move from their home, in the malaria belt, to a Western industrialised country. Thus ethnic Pakistani thalassaemia carriers and their descendants are viewed, from a biomedical perspective, as 'defective', or *at-risk* when compared to the standard[8] human. Added to this, a cultural preference for marriage to first cousins (FCM) puts ethnic Pakistanis, in the eyes of biomedicine, further at-risk. Such

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[5] This film is based on Philip K. Dick's Sci-fi novel *Do Androids Dream of Electric Sheep* (1968), set in San Francisco in 2021.
[6] Fox TV; also a book, Collins, M.A. (2003) *Before the Dawn* (London: Mass Market Paper Back), set in Seattle in 2019.
[7] *Changing Genes*, The St. Leonard's Lecture, Lecture Hall A, Purdy Building, 4th June 2003.
[8] See Law & Hassard (1999,214).

matters of risk form the first thread of my argument and are an important theme in my thesis. New Genetics impacts on this in relation to the ethical implications surrounding attempts by Health Professionals to eradicate the thalassaemia mutation from the genome, particularly as this mutation is predominantly found in South Asian ethnic groups. I later discovered this was also a concern shared by Professor Winston, who argues that such eradication may not be in the best interests of humanity.[9]

The second thread of the thesis, *audit culture,* impacts and focuses this tension further. What I call the 'QA[10] generation' took power by stealth. We now operate within a milieu of *best practice*, *auditable evidence trails* and a climate rife with the fear of litigation. I argue that QA's obsession with outcomes and performance targets has disadvantaged many groups within British society and will focus on the effects that this professionalisation of the world has had on the outlook and life chances of the people I have studied. I further argue that the very act of using best practice to address *institutional racism* in the British National Health Service (NHS) has in itself created a 'bow wave' of institutional racism within the organisation.

Thus the binate thread which draws together the issues and concerns outlined above related to the differing perceptions between ethnic Pakistanis and Health Professionals of risk (or the ascription of at-risk status) and audit culture. To better understand the stances taken by the two sides I shall be considering the enculturation processes – that is, Islam and *doublerootedness*[11] in the case of the ethnic Pakistani population, and the education, training and other processes encountered in the trajectories of Health Professionals throughout their careers. I argue that the evidence points towards the existence of institutional racism, unintentionally driven by the current audit culture practices. This in turn skews perceptions of risk, due to miscommunication, and problematises effective, person centred, risk management strategies. I use the Mendelian recessive which causes thalassaemia as a tool in

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[9] 'Changing Genes', The St. Leonard's Lecture, Lecture Hall A, Purdy Building, 4th June 2003.
[10] Quality Assurance
[11] See Werbner 1990.

an attempt to bring into focus these complex, and at times apparently disparate, issues surrounding risk in this setting.

As I discuss more fully in Chapter One my thesis adopts a narrative style as that offered the most appropriate vehicle for the informants' narratives. As I began to reflect during the writing up process it became clear that I had also become part of the process as my questions led to questions being asked of me in return, and avenues of research were suggested from these interactions between myself and the informants.

The people:

The ethnography from this study comes from fieldwork among ethnic Pakistanis and Health Professionals in two locations: Riverside (in Northeast England) and Central Scotland. I shall introduce these locations in detail in the next chapter but for the moment would like to reflect on the nomenclature I shall use relating to these two sets of people and also on why I am speaking of them as being 'two sides'. I should say that no labelling for these people is totally free from ironies and contradictions, but some labelling is necessary, as a tool for analysis. Moreover the employment of existing terms (e.g. *ethnic*, Pakistani), providing they are clearly defined, may be less confusing in the end than proliferating yet more terms.

The legacies of the post-colonial political landscape mean that, even today, data sets compiled by state institutions tend to lump *Pakistanis*, *Bangladeshis* and *Indians* into one homogeneous block – 'South Asians'. This is often problematic. I am using the term 'ethnic Pakistanis' to delimit one half of the people I studied, and this itself needs to be defended. Identities of course are a complex matter, and in different situations the people concerned see themselves as British, or Muslim, or working class, or urban/rural dwellers, in addition to Pakistani. A central point of argument in this thesis is that in the health care context the majority of these people, notably my main informants, those of childbearing age, see themselves as *British*, and accordingly should be viewed and treated in the same manner as other members of British society. This is in spite of the state apparatus and Health

Professionals, who simply refer to these people as Pakistani, thus connoting an *otherness*. That said, as in the case of all Britons, these people are embedded in a particular historical and cultural background that has a bearing on their special orientation to the health care system. This special orientation is what I am concerned with in this study, and by virtue of my informants' particular in-common background experiences I feel that *ethnic Pakistani* is appropriate as a label for these people. The *ethnic* prefix signals that these people are, in one sense, British.

As to the label *Health Professionals*, this is less contentious, for it is the term used by the people themselves to describe themselves in the health care context, and also the term by which the state, and thus much of academia, categorises them. Another term that is now often being used as a descriptor for this category is 'professionals allied to medicine' which is, I suggest, an audit culture attempt at developing some sense of *esprit de corps* within an oft times divided or hierarchical work group. But I am not aware of any particular issues of concern regarding the term Health Professionals, so I will not discuss my choice further here.

Tension between ethnic Pakistanis and Health Professionals, which I have mentioned, basically refers to different cultural orientations towards health care that have a significant bearing on health care processes where ethnic Pakistanis are concerned. This focus, which concentrates on the attendant interactions and misunderstandings across the health care divide, warrants me referring to the two categories of people as *sides*.

Whether ethnic Pakistanis and Health Professionals make up discrete groups or communities in the sociological sense is another matter (Bourke 1994; Cohen 1985; Hillery 1955; Murphy 1996; Overing and Rapport 2000; Redfield 1960). I believe it is not useful to say that they do, and so a lengthy discussion of the social science relating to these terms would be too involved or tangential to embark upon here. At the local level of things (e.g. in Riverside) the ethnic Pakistanis never assemble all together as one organised body - they are not a group. Likewise may be said of the Health Professionals. Equally at the local level, it

would be hard to assert that Riverside ethnic Pakistanis together make up a 'community', say in Cohen's symbolic sense of the term (Cohen 1985). There are no symbols that one can think of which this heterogeneous body of people all share and which are at the same time exclusive to them. Again, the same can be said of Health Professionals. What one can say, however, is that each side constitutes a distinct category of people: for example, in relation to health care interactions, ethnic Pakistanis are objectively in the same predicament. Paradoxically the reason why this is so is because in their attitudes and behaviour to one another both sides treat the other side as an objective homogeneous grouping, and indeed frequently label this grouping as community - thus Health Professionals will speak of the Pakistani community.

I will use the term 'community' from time to time in the thesis. This is when informants use the term, including when they are describing groupings they see themselves as part of. As none of those I talked with during the research were social scientists I suggest they have no sense of a sociological concept of community, and therefore that their use of the word is in the common or garden sense corresponding to the meaning in any good quality dictionary. However this meaning is close to what Cohen has in mind:

> '...the reality of community lies in its members' perception of the vitality of its culture. People construct community symbolically, making it a resource and repository of meaning, and a referent for their identity.'
>
> (Cohen 1985, 118)

Thus informants speak of the health community, the midwife community or the ethnic community.

Some reflections on Islam:

My informants on the ethnic Pakistani side were almost entirely practising Muslims; this was also the case for many informants on the Health Professional side. Thus Islam features within this thesis. It could be no other way: Islam is central to the lives of Muslims in a way that is hard to grasp for non-Muslims, and here I include myself. I read many texts

on Islam and Muslims throughout the research in an attempt to understand the views my informants were espousing and to understand how Islam impacted on the issues herein. The facts of Islam are contextually necessary for the arguments of this thesis and I discuss them as necessary as the thesis unfolds. This contextualisation is undertaken to allow readers to appreciate a very important aspect of the cultural milieu in which my arguments are set. In many ways this format mirrors the discourse that is Islam.

There are many interpretations of Islam and I will suggest herein that some, told to me by my informants, stem from tradition rather than the *Qur'an* or *Hadith*. This may well be true, and definitions given by my informants may not be those currently held in academia[12], however, they are the views and beliefs of my informants, and it is their world view that I sought in my research. Thus, in this regard, I again follow Fardon's (1992) lead and position myself as a *conventionalist*[13] with regard to views of Islam in so far as I discuss them.

One issue that recurred in the discussions I had with both ethnic Pakistanis and Health Professionals was related to the doctrinal aspects of Islam, for example, Islamic ideas relating to human conception and birth. Eickelman and Piscatori suggest, and my research supports their contention, that the permanence of doctrine itself is a conceptual fiction promulgated by those who wish to maintain their position of power and influence (Eickelman & Piscatori 1996, 16). Islamic traditions are constantly being reinterpreted (see also Asad 1986; Eickelman & Piscatori 1996, 37). Indeed, Asad suggests that the whole of Islam is a continual discourse (Asad 1986, 14-15). The fact of the matter is that doctrinal prescriptions are only one factor and family, ethnicity, class, gender and bureaucratic access also play a part in the mediation of social affairs and are of equal importance (Eickelman & Piscatori 1996, 17). For example, the pilgrimage to Makkah may be doctrinal, but the motor for making the journey may well be a way of improving social status or some other corporeal advantage.

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[12] Thus not underpinned by academic texts.
[13] I follow the conventions of those I am studying.

As well as all this, the dichotomies of social analysis, for example public/private or internal/external or high/low politics, often occlude more than they reveal. These fixed markers deflect analysis from the constant reinterpretation of social and political networks by Muslims in various contexts (Eickelman & Piscatori 1996, x). Furthermore, static and unreflective interpretations of Islam often lead to presumptions that Muslims' relations with others may be hostile or that Muslim interpretations of issues are inevitably arbitrary or authoritarian (Eickelman & Piscatori 1996, 164).

I talk of Muslims as being involved in politics within this thesis. By this I do not mean standing as candidates for election to public office, but rather their involvement in acquiring resources within the wider social milieu – what has been described by Wright (1998) as the politicisation of culture. Many of the these issues are not of themselves political but rather become so when they are transformed into a public symbol – for example, the funding and running of the Standaira Centre in North Shore (Riverside). These actions become political not because they are involved in challenges to state authority, but because they involve understandings of and wishes for social order. These issues are 'Muslim' because they relate to wider issues of tradition and practices that are based in shared cultural backgrounds (cf. Eickelman & Piscatori 1996, 4).

Family is so valued within the Muslim world that economic and social relations revolve around it (Eickelman & Piscatori 1996, 7). The religious and moral meanings invested in family allow Muslims to assess whether government and the wider society fit within the moral and thus Islamic order. On the other hand, governments have to negotiate and mediate differences among various groups within society. Often, as in the case of the French government's position regarding the *hijaab*,[14] the state assumes that politics can be reduced to the use of legitimate force or allocation of material interests (Eickelman & Piscatori 1996, 8). I will suggest that this may be so with regard to thalassaemia and the

[14] Some nation states, for example France, have attempted to prevent Muslim girls from wearing the traditional Muslim scarf (*hijaab)* when attending school (Eickelman & Piscatori 1996, 3-4)

solutions suggested by the British state, in the form of the NHS, towards solving this perceived 'problem'.

Thus Muslim politics has multiple and shifting contexts, as with any other grouping within contemporary society. Perhaps the most significant factor is context and throughout this thesis I have attempted to consider the impact of context both on individual actors and also with regard to the encounter between ethnic Pakistanis and Health Professionals. However, I do not argue that the issues discussed are uniquely Muslim and much of what is discussed has implications for the wider society within Britain. That said, much of what I talk about lies within the context of perceptions of Islam by both sides. As Eickelman and Piscatori have rightly suggested:

> '…one Muslim's image can be another's "counter image"…'
>
> (Eickelman & Piscatori 1996, 21. Also see Asad 1986, 2)

This is often the case when, as I will show, Imam held one understanding of the *Qur'an* and lay ethnic Pakistani men held another. So how much more problematic is it for non-Muslims – in this instance Health Professionals[15] – to grasp the complexities of Islam as it impacts on the temporal realm?

Asad (1986) has enquired into the question of an *anthropology of Islam.* He suggests three possible answers to the question: (i) there is no such theoretical object as Islam; (ii) Islam is an anthropological label for heterogeneous collections of '…beliefs, artifacts, customs [and] morals…' designated as *Islamic* by informants (1986, 14); (iii) an historical totality that organises aspects of social life. That is to suggest an Islam that is in some sense hegemonic within the temporal realm.[16] His conclusion has to be that there is no such thing as an 'anthropology of Islam' (Asad 1986, 2). We are rather dealing with a discursive tradition whereby instituted practices equate to a conceptualised past. Asad argues:

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[15] Although several Health Professionals I talked with were also Muslims.
[16] Social structure, religious belief and political behaviour (see Asad 1986, 2).

> '...a practice is Islamic because it is authorised by the discursive traditions of Islam...'
>
> (Asad 1986, 15)

But this is as far down this cul-de-sac as I intend to travel within this thesis.

However, one area that Asad (1986, 13) discusses which is germane to the argument of this thesis is the conception of a totalitarian Islam. Some (Lewis, Gellner et al, cited in Asad 1986) have even made comparisons between Marxism and Islam. Asad points out that few, if any, Muslim societies had *Shari'a* Law governing more than a fragment of social life. Modern secular states are much more invasive in their effective control of populations than any Islamic state in history. The totalitarian and in many ways 'rural' image of Islam, often voiced by informants from the Health Professional side, has suggested that Islam is against technologies and innovations. Eickelman and Piscatori use a powerful example to evidence why this claim is false and use the archetypal Islamic 'bogyman' Ayatollah Khomeini who stated plainly, in the Iranian constitution, that Islam emphasises science and industry (Eickelman & Piscatori 1996, 22). Furthermore, in Saudi Arabia, a conservative Muslim state, legal reforms routinely occur often with the invocation of *maslaha 'amma* (public interest) (Eickelman & Piscatori 1996, 26). All Muslims agree the *Qur'an* is the direct word of Allah and thus immutable, the *Hadith* is regarded as a template '...for action in the present...' (Eickelman & Piscatori 1996, 28). So, tradition is consciously modified and manipulated, this often occurs in the guise of a return to a more legitimate earlier practice. This was often observed by my informants' use of the *Hadith* to explain their position on issues during our conversations, particularly in coming to terms with or explaining technologies related to the New Genetics and Islam.

Throughout this thesis I, or rather my informants, use the term *Inshallah*[17] - 'if Allah wills'. What importance does this phrase have for Muslims, and how is it used? I suggest that this single phrase is a significant example of an outward demonstration of the centrality of Islam to the daily lives of Muslims. The phrase is frequently used by Muslims, even when

[17] In full: *In Sha Allah* (Houtsma et al 1927, 511).

there is little doubt of an outcome, and is based upon *Qur'an* xviii 23 and xlviii 27 (Houtsma et al 1927, 511). In both instances *Inshallah* is used by the Prophet (PBUH) to Allah even when the outcome is certain (ibid). Houtsma et al (1927) cite three circumstances when people use the phrase: (i) in cases where doubt may really enter, (ii) to show modesty in replying to a question or remark which flatters, (iii) to show good manners towards Allah by submitting verbally and formally to his will. The last use also gains a blessing towards paradise. Essentially the phrase is used, by Muslims, as an expression of a hope or desire.

Appendix 7 contains an exegesis of Islamic terms used within this thesis.

Orientation:

I read widely in an attempt to gain some insight into Islam and the South Asian population during the early stages of this research. As background I found particularly relevant Gardner's (1995) *Global Migrants Local Lives* regarding this population's continued link with the Indian subcontinent, particularly the practice by many people of frequent returns 'home', and also the cultural milieu that contextualises South Asian life in Britain.[18] I also read texts which were specific to the particular people I would study, for example, Maan (1992) on South Asians in Scotland and Lawless (1995) on those settled in northeast England. Both authors knew the specific Muslim groups I would work with intimately. I explored the work of Bhopal et al (1998a),Cauquelin et al (1998), Knott (1997), Malik (1998), Malik (2000)Rizvi et al (1999), whose discussions of both Islam and Pakistanis resident in the UK were most insightful and provided a sound base for my research. I also examined published descriptions of birth pollution, health, genetics, thalassaemia and the contexts and controversies that surrounded genetics, particularly the adaptive mutation of thalassaemia, and the population said to be affected by it.[19] In addition I looked at the work of authors who have illuminated the debates in anthropology around

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[18] For example, by Anwar 1990; Ballard 1977, 1990, 1994; Baumann 1999; Bradby 1999; Carrier 1995; Cramer 1997; Currer 1986; Gardner & Shaker 1994; Hussain 1998, 1998a; Lewis 1994; McLoughlin & Kalra 1999; Madhok et al 1998; Martineau & White 1998; Musallam 1983; Robinson 1986, 1990; Shaw 1988, 1989, 1994, 2000a, 2000b, 2001, 2002, 2003; Uberoi 1994; Werbner 1990, 1996, 1999.

[19] Notably Ahmad 1991, 1993, 1994, 1996, 2000; Atkin 1998, 2000; Helman 1990a; Lenaghan 1998; Modell 1990, 1992a, 1992b, 1994, 1996, 1997, 1998, 1999, 2000; Oakley 1984; Qureshi 1990; Richards & Marteau 1996; Sinha et al 1997.

first cousin marriage and kinship.[20] Finally, I read many, many other research papers, the most relevant ones of which I will acknowledge during the course of the thesis.

The thesis is divided into four parts and eleven chapters, into which ethnography and analysis naturally fell. Part one is divided into two chapters, the first discussing broad theoretical and methodological issues, the second outlining issues around cultural and conceptual matters relating to the Health Professional and ethnic Pakistani sides. The second part is divided into four chapters, looking at relevant issues relating to risk, notions of ethnicity and health, the professional culture of Health Professionals and the cultural world of ethic Pakistanis in the UK. These chapters show how enculturation sets in place attitudes and values which then inform the actions and reaction of the two sides. Part three consists of three chapters and considers the linkages between risk and audit, the relation between audit control and the language myth, and finally, the New Genetics. Here I discuss how the two sides perceive risk and genetics and how their enculturation impacts on the issues. Part four is divided into two chapters, firstly looking at the performance of the audit/risk dance which deals with the impact of protocols and guidelines on the medical encounter between the two sides and secondly at the evidence that, I argue, dispels the *language myth* concerning the competence of ethnic Pakistanis in speaking English.

I shall conclude that audit culture coupled with differing senses of risk have created barriers between ethnic Pakistanis and Health Professionals that are institutionally racist in their performance. This centres around the 'language myth. I suggest that attempts by Health Professionals to meet perceived patient need and adhere to protocols regarding translation lead to institutional racism, a problem which the very processes I shall be describing are aimed at solving. This argument is novel and does not appear to be commonly argued in the literature. Both sides are at-risk from the very processes that are designed to protect them from risk. I finish by offering some recommendations that identify some tentative steps towards a solution and indicate the need for further research.

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[20] These texts include Carsten 2000; Donnan 1988, 1994; Fox 1983; Holy 1996; Leach 1961, 1971; Panter-Brick 1991, 1997; Schneider 1984; Shaw 1988, 1994, 2000b, 2001.

Part One

Basic Ideas and Concepts

CHAPTER ONE

BACKGROUND AND THEORY

Postmodernism: a theory without theory – but it does seem to fit...

I began this odyssey as a slightly hoary Marxist historian and arrived at my present *postmodern* narrative anthropological *karma* having considered a variety of theoretical perspectives along the way. I asked my supervisor how Fardon (1992), whose essay I had read in a postmodernist anthology (Doherty et al 1992), positioned himself theoretically. He said that Fardon had described himself as a *conventionalist*; that is to say that he followed the conventions of whichever group he was working with at the time. Thus I locate myself within the mainstream of anthropology. I still believe that investigation of the relationship to the means of production is, in the broad sweep of society, a powerful analytical tool. However, this is not the venue for such a discussion and I will stick to my postmodern - conventionalist – position as I feel it is best able to describe the lives of the many informants, on both sides, with whom I have worked over the duration of this research.

After the submission of my first draft of this thesis I was 'accused', by my supervisor, of being postmodern, something I had explicitly made clear was not the case in that draft. I read the suggested introductory text on postmodernism and several others in addition. To my surprise I found that there was some very strong resonance between my thesis methodology and its arguments which fit within the realms of the postmodernist project (Doherty et al 1992) – particularly those argued by Baudrillard (1983). This time I hope to explain my theoretical position a little more clearly. Although I, along with at least one other anthropologist, Fardon (1992), remain somewhat unconvinced that postmodernism is a distinct and 'free-standing' sociological theory. What I am suggesting is that the *Grand Theories* are not the most appropriate tools to apprehend either my arguments or my informants' positions. However, I remain convinced that the Grand Theories are, in the majority of cases, still valuable tools with which to examine the broad stroke of society. My

narrative, for that is the way this thesis wanted to be written, is located in a more local space. In my previous *karma* I was an historian (in many ways this is still the case) but now I situate myself as an anthropologist. The main reason for this statement is that it goes some way to explaining two things. Firstly, why I perceive anthropology in the way I do, and secondly, how this informs my sense of the *anthropological method.* Narrative is, for me, one of the main strengths of the discipline and one that I have found to be most effective in apprehending the data that I have gathered. It has also allowed me to analyse that data and I hope make that analysis reflect the views of my informants. I will now consider how this fits with the theoretical and methodological framework of my project.

Firstly, I undertake a brief discussion of my understanding of postmodernism as definitions are, to say the least, heterogeneous (see Doherty et al 1992, 2). For many postmodernists the very question, "What is postmodernism?", is irrelevant, their concern is rather "What does postmodernism do?" (ibid 19). Here I outline a very basic form of postmodernism and then explain how I see this in relation to my project. As far as I can see, the term postmodernism seems first to have been used to describe the reaction against the (Western) modernist architectural style (ibid 3) – particularly the work of Charles-Edouard Jeanneret (pseudonym Le Corbusier) and the post-war tower blocks for which he was renowned and which he conceived of as 'machines for living'. The postmodern architects argued for a return to more traditional forms of architecture. For this school postmodern was a return to the past – a Golden Age of European pre-Enlightenment forms (ibid 3). From this postmodernity sprang the postmodernism which is now part of the social science milieu. I have argued elsewhere (Murphy 1996) that the nineteen-eighties were the heyday of Heritage Culture – vast sums of money were spent on projects which researched and in many cases attempted literally to reconstruct or relive past times. These projects were, for the most part, researched by people who viewed the 'past' through rose tinted glass. In this sense postmodernism is yet another attempt to recreate a mythical past, not a progression but an attempt to return to a time before the Enlightenment Project – an aim which is far

from 'post-modern' and also not useful in discussing society in the twenty-first century. A century much vaunted by the likes of Gerry Anderson (creator of Thunderbirds, among other things) as a Golden Age of technology to come - perhaps the most popular modernist dream. A dream largely wiped out by Thatcherism and Reaganomics by the end of the twentieth century.

Essentially, all of the 'isms' that postmodernism claims to succeed had certain strands in common, for example, an interest in industrialization or society or the use of scientific analysis as models to describe the 'big picture' – the so called 'metanarrative' criticised by postmodernist commentators. Beliefs in progress and science are perhaps the strongest of these common threads of modernity – the Enlightenment Project in short. For postmodernist theorists this project has been abandoned. People no longer believe in the inevitable progress promised by the third quarter of the twentieth century. Science was to solve all of the world's problems, yet society is losing faith in these promises – pessimism has become the order of the day. By the nineteen-seventies the bubble had burst, and according to Charles Jencks (Haralambos 1995, 908) modernism ended in 1972, with the demolition of the Pruitt-Igoe housing project in St Louis (Doherty et al 1992, 3). We have, according to the postmodern perspective, lost faith in grand plans, and now diversity is the norm.

Lyotard, the French postmodern theorist, suggests that language games are now used to legitimate or justify people's behaviour in contemporary society. In these games people attempt to assert their position as right or true. The aim of the game is to use utterances, the moves in the game, to win the game – that is, to have their version of the truth as accepted or right. This is often accomplished through narrative – stories, myths and tales become truth (and to an extent legitimated as scientific) within the process of game playing. I think this is exemplified in the case of the manoeuvrings around the New Genetics or for that matter what I describe later as the language myth. What before were performed within the metanarratives of science or the state are now performed by individual actors, within the

postmodern world. It has been said that postmodern anthropology has become '...the study of man "talking"...' (Tyler 1987, 171).

It has been suggested that there are two clear characteristics of the postmodern universe. The first is that the search for truth, in any objective sense, has now been abandoned as knowledge fragments into myriad language games, games that are the specific realms of bounded areas of scientific or social realities. In the current social milieu diversity, rather than one overarching truth, is now the order of the day in society. Secondly, denotative language games are replaced with a technical discourse, a discourse often discrete to small numbers of an increasingly fragmented society. It is no longer a question of whether a thing is objectively the case, but rather is it useful or efficient. This again returns us to Lyotard's language games and winning by having your version accepted and thus legitimated as 'true'. It is no longer human activity that is the pivot but rather it is the technical means through which this is achieved. I argue that audit culture is an exemplar of such technical means. I outline more fully what I understand by this in part three. Thus in universities research has become geared around the production of knowledge that is saleable. One could suggest that this is merely a legitimation of the capitalist system, were one to analyse Lyotard from a Marxist perspective (cf. Jameson 1991).

Baudrillard (1983) is a Hyperrealist, and often seen as being a postmodern theorist. He also sees that (Western) society has now entered a new phase, but is somewhat more pessimistic than Lyotard in his analysis. Whereas Lyotard sees the postmodern world as liberating for the individual, Baudrillard sees the postmodern landscape as a trap from which there is no escape. My argument in this thesis suggests this may well be the case with audit culture within the wider British milieu. Baudrillard is also critical of Marxism when he suggests that it is no longer the relationship to the means of production that is important but rather the buying and selling of symbols and images that is in evidence. These things are no longer anchored to a material reality. Material things are no longer linked to their material selves but to image projection. This can be seen in political parties and car ownership: it is

no longer about how fast a car can go or what change is brought about by government but what these things say about image and lifestyle. Again I argue that this is the case with the interactions between the two sides I have worked with for this project.

Relevant to this, Baudrillard (1983) suggests that human culture has passed through four main stages. In the first stage signs, that is words and images, reflect the basic reality of the world. In the second stage signs begin to mask or pervert some of the basic realities; though distorted there still remain linkages between sign and reality. In the third stage signs may mask the absence of some basic reality – one example is icons disguising the fact that god does not exist. Finally, signs bear no relation to reality – this sign has become a *simulacrum.* A simulacrum is an image that does not exist, nor has it ever existed. These free floating images are produced and exchanged in modern society, yet have no relation or connection to any real thing. Baudrillard suggests that things, taken from their original context, become *simulacra* or merely distorted representations (cf. Rapport & Overing 2000, 296-7). I will argue that audit culture exemplifies what Baudrillard has described – everything is image and has little or no relationship to reality. The language (signs) of audit is itself taken out of its true, or original, context and is an almost perfect example of what Baudrillard has called simulacra – even down to the recontextualising of the very word.

Baudrillard is quite pessimistic when he suggests that it is now impossible to grasp reality in a world that is entirely constructed of image and no substance. I suggest that the milieu that I describe in this thesis is in many ways illustrative of how, through increasing layers of audit culture, the interaction between large organisations and the individual and to some extent between individuals, has become image based, a simulacra, and has few links to a previously accepted reality. When Baudrillard suggests that power is no longer unequal, it has just disappeared, I am inclined, supported by the evidence of my research, to agree. We, again suggested by Baudrillard, are all trapped in some sort of prison with little freedom to change things and condemned constantly to exchange meaningless signs in order to survive

within a society that has lost its grip on the real world – audit has made us all the consummate simulacra.

Narrative:

This thesis is a combination of a series of actions and interactions between me and my informants over time. Clearly, these interactions shaped the research. For example, many people I initially spoke to were not aware of thalassaemia and as a result of contact with me became aware. Thus a two way process of reciprocity continued throughout my fieldwork and in many instances beyond for I revisited some informants during the writing-up process as patterns began to emerge from the data or supplementary questions needed to be asked for clarification. How to apprehend this complex data? After many attempts at writing up in various styles the one I found most effective was that of narrative as it has allowed me to explore and reflect upon the whole process and how the various actors, including me, viewed their universe and that of others.

According to Kerby (1991, 39), narrative is the telling of a series of temporal events within which a meaningful sequence is presented and in such an order that if the sequence were changed the meaning would be altered. This, I suggest, is not necessarily the case with regard to a story. Thus narrative derives its intellectual rigour and temporal expanses are made meaningful by the orderly sequencing of events (Rapport & Overing 2000, 284).

Relaying my research in narrative terms has allowed self-reflection on both the data and my role in its collection and interpretation (see Rapport & Overing 2000, 27). More specifically, it has allowed me to focus on the particular - the *local* issues that affect my informants in their daily lives. Perhaps the biggest single boon from using this style of writing in this thesis is that it is not 'time-line' dependant. By this I mean that linkages between seemingly disparate events and data were made possible that might not have been the case had another method of production been adopted. Memory, which represents a lasting chronicle of the temporal discourse (Rapport & Overing 2000, 77), importantly articulates this possibility. That is to say:

> '...our experience is illuminated by 'recollection' from memory: knowledge is recollection. When we narrate the ongoing story... we recollect particular images, stopping the flow of memory's stream at certain points, slicing off segments or abstracting certain general features and elements from it...'
>
> (Rapport & Overing 2000, 77)

For example, many events and things lay half-forgotten during the course of the research only to be remembered at a later date, when seemingly insignificant happenings gained significance when juxtaposed with other events or utterances by informants and of events that occurred during the writing up of the thesis.

Narrative was, with hindsight, the obvious style in which to convey an anthropological thesis. Human beings, as Roland Barthes concluded, are '...narrating animals...' (Barthes cited in Rapport & Overing 2000, 283). Narrative is universal and has been present throughout human history and in all cultures (ibid). Narrative is performed by way of language, image and gesture and thought (we all think in narratives) – narrative is truly ubiquitous. In narrative we locate and legitimate ourselves, and our actions, within the wider sweep of our society and the broad sweep of humankind. Anthropologists have always written, and thus constructed, social reality and in recent times there has become a greater appreciation of this fact. As Rapport and Overing have suggested:

> 'This makes of narrative a powerful tool, a means of eschewing the experience of fragmentation and of structuring the world over time; narrative is an instrument of doing as well as saying...' (Rapport & Overing 2000, 284)

Narrative allows for the sequencing of temporal events which then may be apprehended and made meaningful to the individual. We are able to become aware of the various relationships between ourselves, events and others – a comparison with the narrated world (outside) and the *real* world that we live in maintains the many complex, and often fragmented, sets of relationships which we encounter in our lives (ibid 283-6). Our stories interlink with those of others and form new narratives and our world view is accordingly modified. This perhaps

is the strongest reason for my use of narrative as it allows for the apprehension of this modification process which in turn describes my fieldwork. As Barthes (cited in Rapport & Overing 2000, 287) has suggested narratives are little more than '...a tissue of quotations...' – also an apt description of ethnographies.

As for the two sides that I worked with, they both deal heavily in the narrative form. The ethnic Pakistanis were also mainly Muslim and understood their world through the narrative of the *Qur'an* and the *Hadith*[21]. Very often I was literally told stories to illustrate or illuminate a point within the narrative of an individual. The other side, Health Professionals, have their narratives of science and of certainty and also interact with their patients via the narrative form. It is how they construct their diagnosis, whereby they mesh the two narratives into a third narrative: the diagnosis (See Atkinson 1994, 127-8). The whole process of the medical encounter becomes a storytelling event (ibid) – a method in which disparate groups of individuals organise, present and remember information and so understand the world more completely and perform their roles within society. Rapport and Overing (2000, 288) suggest that narration determines collective modes of perception which allow cultural groups to share ways of thinking about and framing experiences, thus coming to share a collective memory.

However, this presupposes that all of the actors experience the narrative in a similar way. I will suggest that matters are much more complex and often rooted in the ethnocentric perceptions of self and other. By this I mean that very often the two sides believe that the other understands the world in a similar way; after all they have shared narrative events. Again the reality, explored herein via my narrative, is often somewhat at odds with this belief. If narrative allows the '...creating of meaning out of experience...' (Rapport & Overing (2000, 288), I suggest, with regard to the two sides studied in this research that the meaning of the experience is often contested. Thus, while Health Professionals see the temporal/secular implications of the haemoglobinopathies, ethnic Pakistanis are concerned with the spiritual.

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[21] The recorded sayings of the Prophet (PBUH) (Eickelman & Piscatori 1996, 21).

Rapport and Overing have indeed argued:

> '…individuals continue to write stories which depict their own world-views… a situation of interpretational pluralism…'
>
> (Rapport & Overing 2000, 289-90)

I also agree with Ricoeur (cited in Rapport & Overing 2000, 290) that:

> '…we cannot directly share in those [life experiences] of others, but using imagination and sympathy we can hope to reach out to others via our stories…'
>
> (Rapport & Overing 2000, 290)

It is to this end that I have chosen to write this thesis via the joint narratives of all involved in the research, not excluding myself.

As I have already said, human beings think in narrative. This is no more so than in the medical process. Atkinson (1994) suggests that medicine has a narrative quality in both the practice and understanding of medicine. Clearly, the role of narrative has been recognised by medicine for a long time – for what is the case-history if not a narrative at its most basic form. Medical conditions are thus aligned and constructed from narrative formulae (Atkinson 1994, 110; also Kleinman 1988; Hunter 1991). Kleinman suggests that patients order their experience of illness via narrative forms when assessing what their illness means to both themselves and others (cited in Atkinson 1994, 111). Narrative is used by Health Professionals at all levels and the ability to extemporise is a required skill (cf. Atkinson 1994, 127-8; Shaw 2003).

So, the way the thesis 'wanted to be written' and how the medical discourse is conducted and how Homo Sapiens have located, and continue to locate, themselves within the universe are all encompassed by narrative. Thus the reader is given the option to hear the narratives of the informant, although how these narratives were selected and sequenced is not in the hands of the informant but rather the keyboard of the author (see Rapport & Overing 2000, 238-9). This said, I have made every effort to be true to the spirit of my informants – many of whom I now count as friend or family.

Basic Ideas:

Serendipity is perhaps the best way to describe the beginning of my odyssey and serendipity has continued to favour me throughout this project. The first formative step was taken early in 1998. I attended a conference on *Ethnicity and Health*, which focused my early research interests. At the conference David Weatherall, a haematologist, spoke of thalassaemia as being a '...major global health issue in the next ten years...' The South Asian population was perceived as having a high percentage of carriers of this (adaptive) gene mutation. I also noticed, during that conference, that there seemed to be a tension between the 'white' and the 'black' delegates. This tension, and the discussions I had with many of the black delegates, linked to my conversations with students in Riverside, began to stimulate potential research question(s).

My first 'formal' research question was that submitted as part of the ESRC funding application. The application form allowed for a title of '...not more than 80 characters...' Hence my working title was: *The Changing Cultural Attitudes to Inbreeding within Riverside's Asian Population* – exactly 80 characters long. This title was too clinical to capture what I wanted to research, but it does however incorporate the insertion of the word 'The' into the title after it was pointed out, by a project manager of a South Asian health initiative in Cattletown, that my original title 'Changing Cultural Attitudes...' was somewhat ambiguous and may well cause major misunderstandings and possibly offence.

It had been suggested, by a genetic counsellor (GC) I met at a conference in Oxford, that Ahmad (1994) had identified institutional racism as a possible factor in explaining the poorer than average birth outcome within the 'Pakistani' population in the UK. This was reinforced by much of the literature[22] I read during this period of the project which suggested a causal link between first cousin marriage (FCM), thalassaemia and poor birth outcome. However, as the research progressed this linkage became less clear and one of the

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[22] Including Abdulrazzaq et al 1997; Balarajan et al 1989; Barry & Kirke 1997; Bittles 1983, 1993, 1998; Darr 1988, 1997; Gill & Modell 1997; Hashmi 1997; Hassall et al 1998; Hickman 1999; Honeyman 1987; Hussain 1998; Hussain & Bittles 1998a; Modell & Modell 1992a; Panter-Brick 1991, 1997; Proctor & Smith 1992; Sinha 1997; van den Berghe 1983.

major arguments of this thesis is that audit culture, within the NHS, may also be a significant factor.

The stories relayed in this thesis were told to me over the five years of my research by ethnic Pakistanis and by various Health Professionals in Riverside and Central Scotland. These stories are about people's lives and their interactions with the *other*. They are stories about risk and about the impact of audit culture and about perceptions of the 'other', of health, of illness and of genetics. Why do I think these stories are important to my narrative? They support my contention that both sides are at-risk from various impacts of audit on their lived experiences and that these experiences are, at times, mutable and often context specific. These stories were told to me in people's homes, in their workplaces, in public spaces, over the telephone, during semi-structured interviews and in innumerable conversations. You might ask when these stories were told to me – some were 'one-offs', some were developed over several interviews (in some cases perhaps spanning several years and reflecting the changes experienced over that time), some were told as specific questions rose to prominence, and yet others were told 'on own-initiative' on the part of my informants.

How are these stories used in this thesis? They inform my contention that risk is contextual and dependant on enculturation; they support my argument that audit fails to exculpate the charge of institutional racism within the NHS; they support my contention that the NHS/state is largely wasting money on interpreters and translation of texts for this constituency – 'ticky-box' audit culture is all that is served by these activities; they support my other contention that the National Screening Programme for the Haemoglobinopathies (NSPFTH) is problematic for many of the same reasons. (Haemochromatosis[23] is a much greater public health risk than thalassaemia. Yet this genetic disorder does not warrant a national screening programme). Finally, by the use of audit the state is arguably increasing risk for both minority ethnic groups and Health Professionals in the present, and attempts at

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[23] A hereditary disorder in which iron salts are deposited in the tissues, leading to liver damage, diabetes mellitus, and bronze discoloration of the skin.

eradication of adaptive mutations potentially puts large sections of the population at-risk, in future generations.

One of the issues identified in this research was the perception, or rather misperception, of ethnic minorities, by British civil society. It is claimed that Britain is *multi-cultural*. I will, much along the lines suggested by Baumann (1999), argue that *cultural pluralism* offers a better, more accurate, description of Britain at the beginning of the twenty-first century. This misperception by the state we shall see comes into sharp relief concerning the issues surrounding language and translation for minorities, particularly within the NHS context. The concept multi-cultural has within it the expectation that society is able to share and value the 'other' in all aspects of their existence. This appreciation of the 'other' must include giving equal value to their beliefs, customs, traditions and religions. However, as long as we have *foreign* food aisles in our major supermarkets we cannot begin to lay claim to a multi-cultural society. (Ethnic Pakistanis are the third largest ethnic group in the UK; therefore it is reasonable to argue that curry and *roti* are not a *foreign* food).

Furthermore, in the UK all citizens[24] are said to be equal under the law and therefore in a multi-cultural society minority ethnic groups should not require organisations to work towards gaining civil rights, unlike for example America. The very existence of movements seeking to give voice to minority ethnic issues within the UK, I would argue, offers proof that multi-cultural Britain is mythical. Examples of this anomalous situation are a Black Section in the British Labour Party and a Muslim Parliament. Both institutions are felt necessary to give voice to its members who, apparently, already have an equal voice in their society. I have not met one ethnic Pakistani informant who feels that they belong to an all-embracing multi-cultural society. With regard to ethnic Pakistanis and Health Professionals I will argue that the state creates false divisions between the two sides and demonstrates, via its own audit procedures and protocols, that Britain is far from multi-cultural. Cultural pluralism – many cultures existing within the same social space - offers a much more

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[24] Note: I am aware that, in law, the population of the United Kingdom are subjects of the Queen and that the state apparatus swears allegiance to the Queen, and not the elected government. However, the majority of the population of the UK believe they are citizens. For this reason this thesis will acknowledge that position.

accurate description of UK society. It is arguably all too clear that cultural pluralism is the desired *status quo* for state organisations.

As the research progressed and interview numbers increased I began to see a pattern emerging. Often decisions were being made, about the 'other', based on phenotype. Such decisions were based on apparent 'ethnic' origin. This was the case with protocols demanding snap decisions by Health Professionals. The process of positioning the 'other' via phenotype was also the case from the other perspective. On many occasions during the research my 'dark' skin and full beard led many ethnic Pakistani informants to assume my 'race'. It was said that I '...look like a Pathan...[25]' or '...people will think you are from Saudia[26] with that beard...[27]' - none of these perceptions[28] addresses the reality my white-Northern-European ethnicity. Often snap decisions are used to define how people are treated – not just at the individual level but more significantly at the level of *guidelines* and *protocol* (institutional racism) within the NHS. This is one of the areas that I identified for further investigation.

Racism was, in the early stages of this work, highlighted, in the literature, as being important. But what is racism? Here I agree with Wade that a finite definition of racism, which covers every possible interpretation is extremely difficult and perhaps not desirable, as perceptions continue to be negotiated (Wade 2002, 7-9, 12). However, I take on board Wieviorka's position which counsels that if people refer only to:

> '...nation, traditions and more generally culture, with no references to nature, biology, genetic heritage or blood, it is preferable not to speak of racism.'
>
> (Cited in Wade 2002, 9)

As my research does refer quite specifically to blood and genetic inheritance – and it is at this level that the two sides intersect in my research - I feel that I am justified in using the

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[25] Interviews with Salina, an ethnic Pakistani community development worker.
[26] What many Pakistanis call Saudi Arabia.
[27] Ikramul, head of one of the leading families in the Cattletown 'Pakistani community'. Also several men interviewed in Cakestone.
[28] There were many, many more incidences of these or similar comments being made by many ethnic Pakistanis that I worked with, both in North-eastern England and Scotland.

term racism. However, I do not wish to dwell on a lengthy discussion of racism. Wade (2002) has done so most eloquently and I would point the reader in that direction if further illumination is required. Racism and the legacy of colonialism (cf. Strathern 2000, 84-5; Wade 2002, 3) are unfortunately intertwined in any study of ethnic Pakistanis in Britain today. Thus, from time to time, I will refer to it within the text, but I, along with my informants, do not see it as being central to their discourse, nor is it to my argument. However, institutional racism is central to my thesis.

Many allude to Macpherson's definition of institutional racism; here I feel that a copy of the full version may be useful:

> 'The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantages ethnic minority people.
>
> '[Racism] persists because of the failure of the organisation openly and adequately to recognise and address its existence and causes by policy, example and leadership. Without recognition and action to eliminate such racism it can prevail as part of the ethos or culture of the organisation. It is a corrosive disease.'
>
> (Macpherson 1999)

I have accepted Macpherson's definition of institutional racism for two reasons. Firstly, Alexander (1999) took the definition as her baseline when carrying out her survey of the NHS. The second reason is that it offers a reasonable description of what I am arguing in relation to what I see as institutional racism. On this definition many major organisations in the UK might be described as institutionally racist (cf. Ahmad 1994; Alexander 1999; DoH

1999a, 2000a; Macpherson 1999; Pearson 1994). Alexander (1999) finds the case proven with regard to institutional racism, at all levels, in the NHS.

Macpherson suggests that the collective failure of an organisation to deliver appropriate services because of colour or ethnic origin is an indicator of institutional racism. Furthermore, the organisation must recognise this failure and take action to rectify the matter. Not doing so can allow this failure to become part of the ethos of the organisation. In the case of my research I believe that this is so with regard to issues of language and translation. I will not be arguing that this is malicious, but rather several factors militate against effective solutions being implemented. One of the reasons for this thesis is to highlight the problem, which seems not to have been noticed in the literature to date.

It was evident within the literature that institutional racism may be a much more significant factor in determining birth outcome within the UK ethnic Pakistani population than consanguinity (Ahmad 1994, 426, 1996; Alexander 1999; Bhopal 1998b; Bowler 1993; Cooper 2001; DoH 2000; Pfeffer 1998; Proctor 1992). This is linked to a suggestion, by Health Professionals, that 'Pakistanis' bring ill health upon themselves by their actions or inactions, according to Ahmad (ibid) and further evidenced by work looking at midwives' attitudes to Pakistani clients (Proctor & Smith 1992). One study suggested that there were four main themes to this stereotyping: (i) difficulties in communication with the women; (ii) women's lack of compliance with care and abuse of the service; (iii) their tendency to 'make a fuss about nothing'; (iv) their lack of 'normal maternal instincts' (Ahmad 1994, 426). These perceptions of Pakistani women, held by Health Professionals, are widely evidenced in the literature (Ahmad et al 1993; Proctor et al 1992; Atkin et al 1998). I will be suggesting that Wright's (1998) argument regarding the development of a global politicisation of culture may equally be seen as a trope for the audit culture's reaction to external accusations of racism.

Another key element that has impacted on this research has been the torrent of information regarding what might be loosely called the New Genetics. It has, for me, meant

a constant battle to keep abreast of the current state-of-play during the course of this research. 'Facts' at the beginning of the research changed, mutated or became just plain untrue by the time I came to write up. I argue that if I have struggled with these issues, and it was my primary task, how can busy Health Professionals, let alone lay members of society, keep abreast of this rapidly changing field?

Added to this as my research progressed I found that few people have understood my concerns or had any comprehensive knowledge of thalassaemia. If they had any knowledge it was sketchy or hearsay or direct quotation 'from the book'. Added to this complex mix of genetics and ethnicity were questions about religion (Islam), kinship networks and claimed marriage customs.[29] I found that questions that I had originally intended to address – that is, the changing cultural attitudes to FCM - were all but impossible to apprehend within the timescale of this research. I had planned to look at generational changes in marriage customs in families of the ethnic Pakistanis I met during my fieldwork. However, I found quite early in the project that educated members of the ethnic Pakistani side (doctors and community leaders – the *gatekeepers*) told me:

> 'First cousin marriage would be very rare in five years… and would cease to exist within ten years…'

However, 'working class' ethnic Pakistanis told me they would continue to marry cousins '…forever… it was the religion…'[30] As I did not have ten years to wait and see which 'team' won, I modified my research parameters.

Methods:

Many of my research skills, and concomitant methodologies, were acquired during my previous *karma,* as a social historian, and translated into my current anthropological methods; other skills were developed 'on-the-hoof' or via attendance at relevant workshops along the way. These research methods include participant rapid assessment (PRA), semi-structured in-depth interviews, observer participation, snowball sampling, key-informant

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[29] Concepts that I felt, at the outset of this research, were essential to writing as an anthropologist.
[30] Both of these comments were equally validated during the Scottish phase of the research.

interviewing, questionnaires, life-histories and genealogies, maps, informal conversations (with informants who were already aware that I was engaged in research), letters and e-mails, official (state) datasets, focus groups, gossiping and perhaps the most important method of all - serendipity. I also undertook a survey of the substantial literature in the very broad areas that, at one time or another, constituted my 'field'. The final method in my arsenal was sheer persistence and 'doorstepping' informants in the street. This last was due to the effects of global terrorism impacting in a very local way on my access to the field.

One of the first things that became clear within the ethnic Pakistani side was that once I was 'vouched for' by one person in a locality this 'acceptance' applied to all of their friends and family also, which made snowball sampling much more viable. In Riverside one of these snowballs gained my first contact with a Health Professional. He was the brother-in-law of one of the community development (CD) workers. This solved one of the major problems identified in the early stages of the research – how does a social scientist, an outsider, gain access to the 'closed ranks' of the Health Professional? From here I was able to make more contacts and these snowballed linkages led to contact with Salina, a development worker who had worked with what she called 'the South Asian community' in Riverside for many years. The 'friend of my friend' method worked very well here also and I was able to make effective contacts with many members of the ethnic Pakistani side in the area. Scotland was, however, more problematic, as I shall explain later.

I also undertook the majority of interviews myself in both Riverside and Central Scotland, with Salina as chaperone in the early interviews in Riverside. Some of the interviews, in both areas were, on a few occasions, conducted by my female research assistant if circumstances indicated that my gender was disadvantageous in gaining access to women within the Pakistani category. This role of 'chaperone' had been undertaken by Salina in my initial contacts with women in Riverside more for the benefit of the men rather than any concern felt by the women. After my introduction and acceptance by the people in the locality I was able to meet with women (and men) without any problems. I was the

'anthropologist' and as such was perceived to be no threat - I had apparently become asexual in the men's eyes.

Salina was most helpful in the initial stages of the research and introduced me to the workers in a minority ethnic education project, the Neighbourhood Centre and the Women's Centre. Salina also introduced me to many individual families and translated for me until people were confident enough to talk to me in English. (I made several attempts to learn Urdu and Punjabi myself, but was unable to find a teacher.) This early experience of the translation/language situation became the root of my key argument of this thesis.

I began to attend courses and conferences from early in 1998 and at one of these conferences I met Mohammed, a genetic counsellor, who worked in a nearby city hospital. Mohammed was formative in setting out my approach to the genetic element of the research. He was particularly helpful in providing bibliographic information and sent me copies of relevant articles on thalassaemia and first cousin marriage (FCM) in, what Mohammed described as, 'the South Asian community' in Britain. On another course I met his wife Naheeda (serendipity) who told a very different story to that of her husband with regard to the NHS encounter regarding FCM and thalassaemia. In part it is this juxtaposition of two disparate perspectives from within the ethnic Pakistani side that has driven this research forward.

One of the most important links I made was with the Imams in all of the Muslim coteries in which I have worked. Islam is central to the lives of the ethnic Pakistanis. I was introduced to Mr Kalum, the ethnic Pakistani Imam in North Shore (area of Riverside) where I started the fieldwork, by Salina. Mr Kalum then introduced me to the Imam in the larger conurbation nearby who was a *hafiz.*[31] Mr Kalum even supplied me with a 'guide' for the meeting – my soon to be friend Rauf. When I came to Scotland, one of my first priorities was to attempt to make contact with local mosques and more importantly the Imam – this, as with all of my initial work in Scotland, was initially a little problematic due to the events of

[31] Someone who is able to recite the whole of the Qur'an from memory. Such a person is held in high esteem by Muslims.

September 11th 2001.[32] There were many attacks on Muslims (Daily Record 23/11/02; BBC News 20/9/01, 21/9/01, 22/9/01, 16/10/02; The Sun 29/10/02)[33] around the world in reaction to the terrorist attacks on the USA. No less so in Scotland with an arson attack on the mosque in Edinburgh.

I spent a short period of time in Pakistan and found this invaluable; as without this experience I could never have gained a sense of what 'family' is for ethnic Pakistanis. Furthermore, the trip to Pakistan gave me 'street cred' with the ethnic Pakistanis I met in the UK. It was commented upon that no other researcher, and there have been many before and since, had bothered to travel to Pakistan. The informants saw my making the trip to their 'home' as a very positive event. Finally, my stupidity at travelling when I did (July, with the temperature in the mid-fifties) gave rise to much humour and disarmed the situation on many occasions – especially after the *September Events*. Also my visit to Pakistan gave me a very vivid insight into the performance of risk and in particular non-Western perceptions of risk, and allowed me to gain, first hand, a sense of Werbner's *doublerootedness,* which I shall discuss later (Werbner 1990).

When, finally, I moved into the central Scotland phase, I found that access to the Pakistani side was very difficult and for a while I felt that the research could not be continued. The aftermath of '9/11' was such that the ethnic Pakistanis were very suspicious of a white man asking very personal questions about marriage customs and their possible link with congenital birth defects. I persisted and finally began to make inroads into this population. Then there was the 'Bali Bomb'.[34] Again my research began to be viewed with suspicion. To combat this I began to 'door-step' ethnic Pakistanis in the street and ask for their help in my research. I also went into Indian Restaurants and asked the waiters questions and also asked for their help in my research. The fact that I had been taught by my friend Rauf how to eat properly (like a Pakistani Muslim) went a long way in gaining

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[32] The attack on the World Trade Centre, New York and other USA targets, on September 11th 2001, Commonly known as '9/11'.
[33] These are a very tiny proportion of attacks on Muslims attributed to revenge for '9/11'. There were also attacks on some of my informants.
[34] A further terrorist attack, in Bali, which it was again claimed was the work of 'Muslim extremists'.

people's trust during this tense time. So, in the final stages of the fieldwork I was able to meet and talk with many people both 'out and about' and in one of the mosques, in Scotland.

I was involved in a car crash and my injuries, though not too severe, meant I was unable physically to sit down long enough to type up my thesis. I used some of the time to return to the field in England. I did this for two reasons. The first was to catch up with friends and to fill any gaps in my data. The second, and I think more important, was that several of the women who had taken part in my original research had had babies in the interim. Also, there was now a 'national' prenatal screening programme for the haemoglobinopathies (including thalassaemia) in place. I spoke to many people that I had spoken to previously, but also some new people as personnel in the NHS had moved on and new members had joined or moved into the area. All-in-all I found this brief re-emergence into the Riverside milieu very productive.

I also took this opportunity to revisit the Health Professionals (genetic counsellors and midwives) in Scotland for much the same reasons as my return to Riverside. I was given invaluable insights into the current milieu in Scotland and was able to ask more in-depth questions now that I had the fieldwork under my belt and had an idea of what I was going to argue in the thesis. I found the return visits to be much more fruitful than I had imagined they might be. I seemed to be treated much more as an 'insider' on my return contact. The people were interested in talking about what I had done since we had last met and were happy to give their comments on my new data and new theories.

One unlooked-for group of informants were the medical students at the University of St Andrews. It was in the 'wee-small-hours' that I suddenly realised this group sat at the very interface that I was trying to access. Most of the students I talked to were 'South Asian', but some were white. They were from first, second and third year cohorts and one of the most interesting things was that their perspective showed a marked change as they moved from the 'lay' towards the 'professional'. Their understandings and perceptions

seemed very much altered by the process. Here I was able to meet with young Muslim women unchaperoned. My guess was that they were from more liberal family backgrounds.

One method I found most effective in maintaining links with ethnic Pakistanis in Riverside, problematic due to the extended nature of the fieldwork, was to send *Eid*[35] cards. As my research was in two distinct geographical locations I did not have daily contact with individuals after I had moved location. The sending of *Eid* cards, at the end of *Ramadan*, allowed my name to remain within people's minds and facilitated my smooth reintroduction into the field after a gap of some eighteen months. The cards also caused some informants to telephone me to say thank you for the card. This allowed me to talk to people, but also allowed them to select a time which was convenient to them. Some informants by not responding indicated they did not wish to maintain contact. Thus I was able to maintain contact in an ethical manner. I also conducted my research in some unusual places – for example in the queue outside the Pakistani High Commission, in London, as I waited to apply for my visa, and in aircraft between meals.

Technical notes:

Protocols I used in transcribing the audio-tapes are as follows.

- If an informant put a specific emphasis on a word or phrase then I have *italicised* that word or phrase.
- If the informant has used a word or phrase in a 'novel' manner – quite often as a trope – I have put the word or phrase in inverted commas.
- Occasionally I have left sections out of the transcript and have followed the standard practice of putting three periods into the text at the appropriate point.
- The most frequent use of this method is to 'edit out' any sense of apparent confusion by the individual speaker. I have not changed the sense of what was said by this.

[35] A Muslim festival (full name Eid ul-Fitr) the feast marking the end of the fast of Ramadan. Cards are sent to friends and family who live far away.

- On other occasions I have left these 'fillers' in, much as Hallowell (1999) has done, where it is important to the sense of what is being said.

I have used pseudonyms, and sometimes changed key identifiers to personal circumstances and used amalgams. I am aware that this option is far from a fool-proof method. However, all of my informants agreed to be identified and their real names used within the document. Here I agree with Strathern (2000, 294-5) that the informant is a rational person able to make rational decisions, take responsibility for their own words and actions and give informed consent as part of the interactive process. It is not that I think my informants are in any way incapable of rational thought or are unable to stand by their words and actions; I make these changes for myself as I am unclear where my data may be used or by whom.

> Finally, I have taken a very simple definition of consanguineous marriage: '…the marriage between blood relatives who have at least one common ancestor who is no more remote than a grandparent.' (Seller 1997).[36]

I have chosen not to develop this definition further as it is not necessary in the usage I, and my informants, have used it relative to this thesis.

Ethics and anthropology.

One of the most valuable and influential texts that I consulted when considering the ethical implications of my research was DeVita's (1992) *The Naked Anthropologist*. I read it after my return from Pakistan, when I was at something of a low in my research there having 'failed.' However, when I read some of the chapters dealing with the problems, pitfalls and downright unpredictability of fieldwork I felt a little less low having realised my experiences were not unique – I was not alone. I also gained some insight into what my role as anthropologist was – what I could or should do and more importantly what I should not do. It is all very well trying to set some lofty academic set of rules written by the 'great and the good' (AAA 1998; ASA 1999) but what I needed was some practical guidance. If one

[36] http://www.naresa.ac.lk/other/birth/brn0197.htm

were to adhere strictly to the AAA/ASA guidelines no research could ever be undertaken. DeVita's edited text provided that practical guidance particularly the contributions of Murphy[37] (in DeVita 1992, 173-183) and DeVita[38] (1992, 156-164). I had carried out research using living informants[39] for both my undergraduate and postgraduate work as an historian, so I had an awareness of some of the issues. However, I made many mistakes then which I hope I have not repeated here, the majority of which related to the fact that most history is written about dead people and thus *ethics* comes fairly low on its list of priorities.

Perhaps the single most significant event that formed my ethical stance was the Wellcome Trust postgraduate workshop I attended in 2000. There ethics was central to almost every aspect of the workshop. Meeting with professionals and fellow students was most informative. One of the key practical ethical points I took from this workshop concerned the transcription of interview tapes. In previous research I had had a third person transcribe the tape recordings. It was pointed out that although the informant had given permission for the interview and for that interview to be recorded they had not given permission for a third party to listen to the recording.

I have attempted to give an accurate, warts and all, view of the research undertaken throughout. This is done for two reasons; the first is that the Economic and Social Research Council (ESRC) gave me a grant to undertake research that would make a contribution to knowledge. The second reason is that if I did not make every effort to give an accurate account I would be letting those people down who have entrusted me with their narratives.

I have also used pseudonyms for the place names in a further effort to protect the identities of my informants. Riverside has become 'nationally recognisable' via several current television series and had I used actual place and organisation names the informants may have been much more easily identifiable. My solution is by no means perfect, but it is

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[37] Murphy's insightful discussions around the anthropologist's need to be continually mindful of partisan notions overlaid on anthropological research, by their informants, were very apt in regard to the two sides in my work.

[38] De Vita describes the ethical dilemma that social researchers face with regard to what they see and are told *at the garden gate* – exemplary, but unusable.

[39] This opposed to research carried out into historical events occurring beyond living memory.

the best that I can do. Riverside, which is in Northeast England, was a highly industrialised area – some would argue the cradle of the British Industrial Revolution – and now is in severe industrial and urban decline. Central Scotland presented similar ethical problems with place nomenclature. The dwelling places of ethnic Pakistanis in Scotland range from rural towns to cities. One point of note is that the industrial decline has been less dramatic in the Scottish locations.

Location pseudonyms used in this thesis:

Central Scotland	Northeast England
Bondville	Brownton
Cakestone	Cattleville
Citadel	Endeavour Hospital
City Hospital	Ironopolis
Coldville	Lungton
Integerpool Hospital	North Shore
Jamestown	Oldfort
Judderstone	Riverside
Poundtown	Standaira
	Talcap
	Waterloo Road

Clearly ethical issues are important and most modern codes stem from the post-Nazi period and are aimed at protecting the welfare of participants in research from exploitation by researchers (Holly & Sumner 2002; Lee-Treweek & Linkogle 2000; Mills 2002; Simpson et al 2002). It is accepted that social science research rarely puts informants in physical danger. One of the main aims of the codes, it is claimed, is to gain informed consent from participants and allow them to be empowered by the process.

As Lee-Treweek and Linkogle note, gaining informed consent is more complex than might first appear from the above (Lee-Treweek & Linkogle 2000, 17). I see the notion of informed consent as problematic in its various contexts and return to it later in the thesis. Here I want to talk more about the problems of the researcher being unable to provide

sufficient information, or reassurance, that the data will not be used in ways that might do harm in the future. Once this thesis is written and the viva survived it enters the public domain and even with the attached riders it may still be used in ways that neither I nor those involved in its passage can foresee in the future. Interpretation of any social research by institutions, the media or pressure groups cannot be predicted (Lee-Treweek & Linkogle 2000, 18, 19, 23). I have struggled with this issue from the very first interview on my very first day of fieldwork. I took the advice of Lee-Treweek and Linkogle and undertook an assessment of risks that informants and the wider society might face as a result of my work (Lee-Treweek & Linkogle 2000, 18). Having made such assessment I have put in place as many safeguards as possible and have omitted anything I felt was problematic. I have discussed my thoughts with my supervisors and fellow postgraduates and sought their advice on issues that concerned me. What follows is my attempt to balance these complexities and give voice to my informants, as ethically as I am able.

CHAPTER TWO

CULTURE AND CONCEPTS

Ethnic Pakistanis in Britain and the South Asian Diaspora:

Here I want to outline the nature of the culture and antecedent history of the ethnic Pakistanis in the UK. Their sense of culture – a mix of tradition and Islam which spans two continents – is often seen as being of great importance, especially now the older generation are 'permanently' domiciled in the UK. For this reason, any attempt to research this subject without first trying to come to grips with these influences of the past, in the present and in the future, would be futile. Werbner (1990) has suggested the concept of doublerootedness to describe this state of affairs. What Werbner suggests is that this group maintains a sense of synchronously having a 'foot' in two very different sets of cultural values - a rural Pakistan of 50 years ago and contemporary Britain.

An almost ubiquitous theme throughout the literature (Knott 1997; Lawless 1995; Maan 1992; Shaw 2000; Werbner 1990) on the South Asian diaspora is that most of the early migrants to Britain were sailors, who came piecemeal in the decades before the Second World War. The main driving force for migration in the early days was strictly economic. There had been a long history relating to high rates of unemployment in the rural areas of the South Asian subcontinent. The migrants predominantly took work in the hospitality industry – cooks or boarding house keepers – or in labouring jobs in the heavy industries (Knott 1997, 758; Lawless 1995, 13-14). The men, (for in the *Pioneer* phase of the diaspora only men migrated to the UK), were employed in positions where white workers were not keen to work – so called 'dirty jobs' (cf. Shaw 2000, 38-9). The major diaspora of the twentieth century, especially after the Partition of India in 1947, was thus merely a continuation of a long tradition (Lawless 1995 16-17; Maan 1992). Most of the money earned was sent back home to the family and/or the village.

The money the men sent back home to Pakistan allowed their families to settle debts, build houses, buy land or start businesses. The migrants were industrious, working long hours, and when they had made sufficient money they returned home to Pakistan, returning again to work in the UK if more money was needed by their family. It has been said that Pakistanis can most often be found either half-a-mile or half-a-world from the place they first lived in after entering the UK. That is to say they remain living within half a mile of the place (the *ghetto* theory) or they return home to Pakistan ('half-a-world away'). I would agree that this might have been the case in the past; however, the picture is much more complex today.

The diaspora has not been a smooth process. The 1962 Commonwealth Immigrants Act was the first significant step, by the British state, to stopping immigration and was designed, in part, to slow down entries to the UK from the South Asian subcontinent. There was a rush to 'beat the ban' with a huge influx from the South Asian subcontinent before 1st June 1962 – the last day for unrestricted entry into the UK from the old colonies. However, few of these migrants chose to settle in Scotland. Scotland was far from the main Reception Centres; also employment prospects in Scotland were poorer than elsewhere in Britain (Maan 1994 163).

From the mid-1960s there was a change in the make up of the South Asian population in the UK. The men of the 'pioneer generation', many having left their families behind in South Asia, began to bring their families to the UK. The first family members to come to Britain were the sons, and later they were joined by their wives and daughters (Lawless 1995, 14-15). This move towards family reunions was not uniform across all groups from the subcontinent. Hindu and Sikh men brought their families to the UK much earlier than did the Muslims (Ballard, in Clarke et al 1990). Ballard argues that this is one of the most significant factors in explaining why British Pakistanis tend to be somewhat behind in their social trajectory compared to their fellows from the subcontinent.[40]

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[40] The other reasons are: marriage rules, gender rules and mortuary rites. See Ballard, in Clarke et al (1990).

Reasons for migration, for whatever purpose, are said to be a combination of both push and pull factors. One push factor, for Mirpuris[41], the major grouping of Pakistanis in the UK, is said to be the construction of the Mangla Dam, flooding many of the villages in the Mirpur region of Pakistan in the 1960s.[42] This put further pressure on families reliant on cultivation as land, already at a premium, became an even scarcer commodity in the areas of out-migration. This increased pressure on the land was concomitant with the 1962 Commonwealth Immigrants Act, which acted as a further push to those who were economically driven to migrate.

Pull factors for the economic migrants were powerful as potential earnings in Britain were considerable. Britain was suffering labour shortages after the war and in addition wages were much higher than those paid for similar work in Pakistan. Shaw quotes wages for labourers as being equivalent to 37p per a week in Pakistan compared to £13 for similar work in Birmingham (Shaw 2000, 13). Furthermore, there was a belief that life in the Mother Country would be much better than that in Pakistan – it was widely believed that the '…streets were paved in gold…' (pers. com.). This, coupled with the belief that as British citizens they would be treated as equals, encouraged many of the 'pioneer generation' to leave their homes and families and travel the 4,000 miles to Britain to seek their fortunes.

In *chain migration* the family, or members of the village, would make contributions to pay for one man to travel to Britain to work. He would then send money back to the village to allow another man to travel to the UK to work. Remittances sent to those who remained in Pakistan allowed more men to travel abroad to work and the incoming money greatly improved the economic standing and *izzat*[43] of the family or village in Pakistan (Shaw 2000, 42-3). This was clearly a spiralling process (Maan 1992 159; Ballard in Clarke et al 1990). This set of circumstances accounts for men from the same village of origin being

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[41] Mirpuris are from villages in the district surrounding the town of Mirpur in Azad (free) Kashmir, northern Panjab.
[42] The Dam was completed in 1966.
[43] *Izzat* refers basically to the honour and respect an individual [man] or family group have, particularly as perceived by others within their social realms.

found in the same areas in Britain. It also explains why there are many people with links to a very small number of villages in Pakistan and also why some villages are not represented (Lawless 1995, 18).

Accordingly, there are many stories of foremen, for example in the heavy industries of Riverside, asking existing South Asian workers to find men from their family or village to join them and of the companies sponsoring workers' migration (Lawless 1995, 18 and testimony given to me during interviews and discussions). Men asked their uncles, brothers and members of their *biradari*[44] to come over to work with them.

Lawless suggests two reasons for migrants gravitating to Riverside. Firstly, Ironopolis had a reputation for high wages. However, Lawless's second argument that Mirpuris were from rural Pakistan and therefore preferred to move to Ironopolis as it was smaller than London or the other major cities in the UK (Lawless 1995, 18) is flawed. This is in contradiction of his claim that there was a long tradition of men from rural Mirpur working in large urban centres, '…either in Pakistan or abroad…' (Lawless 1995, 17). The more plausible explanation would be employment opportunities available from the great number of iron and steel related industries alongside the rapidly developing petrochemical industries of the Riverside valley. Lawless suggests that tougher immigration legislation in the early nineteen-sixties sped up migration as people feared that their relatives would not be able to enter Britain (Lawless 1995, 19). Yet he also relates the ease by which informants were able to gain a voucher[45] with either the help of family already in the UK or the support of British employers desperate for workers.

Maan (1992) describes another stratagem used to gain entry to the UK. Men register their kin on college courses in the UK. With the enrolment form in their possession the 'student' could get a visa and enter the UK. Very few, if any, of these students ever attended

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[44] Definitions of *Biradari,* and here I agree with Shaw (2000, 140), depend upon context and can range from a small group of inter-marrying close kin to a *zat* kinship group of almost infinite size. *Biradari* linkages can be, and often are, pragmatic and can be called upon to legitimate unions, say between business partners of differing *zat* who wish to strengthen the partnership by the marriage of their children. Also page iv.

[45] A system which allowed persons to bypass the immigration restrictions providing they had employment and support systems in place. In other words they would not be a drain on the British state.

the course for which they were enrolled (Maan 1992, 158). Undertaking education or formal training would get in the way of the men's primary goal – earning money to send home to help their kin.

From the mid-1960s there was increasingly a period of family consolidation relating to fears of further legislation which would effectively prevent the immigration of families to join relatives already in the UK. This process carried on until perhaps 1980, when most of the exploitable loop-holes in the system had been sealed by the British state. Today very few people are able to get past the British immigration officials based in the subcontinent. Ironically, it was the British attempt to restrict immigration to the UK that caused many people to make the UK their permanent country of residence. Had they been able to continue to return freely to their homes in the sending community, without fear of not being able to return to the UK to boost their family's income when necessary, few would have made the UK their home.

A further source of South Asian immigrants into the UK, which increased during this period, was due to the *Africanisation* policies by the newly emergent African states (Lawless 1995, 20-21). The process occurred as a by-product of decolonialisation processes of the 1960s and on into the 1970s. Indians had migrated to Africa in the 19th century to work for the British in their African colonies. Those 'South Asians' deported by the African states[46] were very often born and bred in Africa[47] and were used to being afforded high status within the country. The South Asians had acted as administrators and clerks for the British and were not well liked in fact because they were reminders of an oppressive colonial past. They were expelled by the new leaders who decided that Africans were going to administer Africa. They either migrated on their own initiative or were literally thrown out without, in many cases, even their personal belongings. The UK government had, in the past, issued them with British passports. Thus many of those expelled from East Africa chose to come to the UK. Most arrived in the UK destitute, carrying only a few possessions.

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[46] Mainly from the East African countries of Kenya, Malawi and Uganda. (A large number of Asians were later expelled from Uganda and they arrived in the early 1970s.)
[47] This was the case for several of those I talked with, in both locations.

Since that time most have regained their 'place' within British society, due to hard work, entrepreneurial skills and adaptability - which are also the characteristics argued to be the key to wider South Asian success within the UK. Lawless describes the long hours worked for very low wages by Pakistanis in Riverside. Hard work, for those recently arrived in Britain from Pakistan, was accepted as a natural and unavoidable fact of life. Lawless (1995, 24) quotes one informant as saying: 'At home in Mirpur, if you didn't work you didn't eat.'

As to Scotland, before World War Two, South Asians living there, who were predominantly Muslims, had tended to work individually and to be spread throughout the length and breadth of the country, most making a living as itinerant peddlers. With the declaration of war they all moved back into the relative safety of the Gorbals area of Glasgow (Maan 1992, 149). Many worked in the munitions industries during the war and were, as munitions workers, given preferential treatment on public transport – a boon they enjoyed. This change in social status led to a generally less submissive group than that of the pre-war communities (Maan 1992, 151). Also, before the war they had avoided mixing with the Scots. However, this changed due to the necessity of mixing with the Scots in air raid shelters and on the factory floor (Maan 1992, 150). This encouraged the development of a mutually beneficial relationship between the two groups. Young South Asians and Scottish girls met during this period and became happily married during the war years (Maan 1992, 151). These experiences and interactions helped South Asians to integrate into wider Scottish society. Maan also suggests that the South Asians integrated with the Scots (Maan 1992, 3) because of the long tradition of Scots people working in India during the Raj. There is also the sense, Maan argues, that the Scots felt like underdogs in relation to the English, as did the South Asians.

When war ended so did privilege on public transport. The South Asians were made redundant from munitions work and returned to pre-war employment patterns – peddling. This return to peddling was due to individual choice. Even though there was a labour shortage in factories the South Asians, of the pioneer phase, did not take the jobs, preferring

to be their own boss (Maan 1992, 153). These new factory jobs were taken by the newcomers of the second phase of the diaspora. Peddling was perceived by them as being too difficult; also racism became a growing consideration (Maan 1992, 153). The Pioneers did not like to work for others. Maan (1992, 153) cites a common saying in the Punjab: '*Udham khaitri, madham bupaar, nakhid chaakri.*' - farming requires initiative and is the best profession, business requires patience and comes next, but service is servitude, and for the servile.

In the 1950s many South Asians moved away from peddling and into more settled jobs. For example, there were shortages of bus drivers and conductors in Citadel so many South Asians took the posts. The South Asians were perceived to be never absent, good timekeepers and hungry for overtime. Some sense of how vital the South Asians were to the transport system in Citadel can be seen in 1965 when India and Pakistan went to war – the day that war was declared, public transport ground to a virtual standstill as the South Asian crews stayed at home waiting for news by their radios and televisions (Maan 1992, 165).

In Scotland, due to this shift in employment patterns, the men bought grocers shops, newsagents, restaurants and wholesale and retail businesses (Maan 1992, 165). The men had been used to working hard with no social life. They worked and slept, then worked again to meet their goals. Those South Asians from that part of pre-Partition India now known as Pakistan are the focus of this thesis. They worked hard, saved fast, bought a house, invited families to join them from Pakistan, and then bought another shop or other business. This practice of saving for the future continued and has made many Pakistani businesses very profitable.

According to Maan (1992), those whose business catered for the South Asian community faired well. Those who tried to do business with the indigenous population did less well initially. People walked out of shops when they saw an Asian face behind the counter. To counter this, shopkeepers opened longer hours and reduced their profit margins. This drew in more customers, but caused problems with other, non-Asian, retailers in the

area. The other (white) retailers put pressure on the wholesalers not to supply Asian shops until they agreed to bring prices in line (Maan 1992, 165). The pragmatic South Asian solution was to use their networks and use wholesalers who were Asian (also see Werbner 1990, 63). Many of the very large South Asian owned wholesalers started life to meet these needs. Similar scenarios are of course reported for Pakistani shopkeepers elsewhere in Britain.

The other strand of the success of ethnic Pakistanis in Britain was the use of internal migration. One example of this can be seen when there was major unemployment for Pakistanis who worked in the mills in Yorkshire and the Midlands. South Asian *biradari* and kinship networks came into play (see also Shaw 2000, 40). Pakistani workers in the Jute Mills in Cakestone, which were suffering labour shortages at the time, contacted families and friends which resulted in many of them migrating to Cakestone to take employment in the mills there (Maan 1992, 171-2). The mills required the working of odd hours and hard manual labour – the South Asians were used to both. One factor that worked in favour of the South Asians in Scotland is that they never took employment in areas favoured by the indigenous population. Thus they were never in conflict for work and were not first out if there was an economic downturn. This is in stark contrast to South Asians working south of the border.

Patterns of employment again changed for many ethnic Pakistanis in Britain, during the 1980s, as unemployment in the traditional industries in Britain became a problem (see also Shaw 2000, 40). Many of the men were unable to continue to send money home to Pakistan due to having no work. The general retrenchment in the traditional, labour intensive, industries like steel-making and the mills, affected South Asians much harder and much earlier than others working in the sector as they lacked transferable skills or qualifications. However, the entrepreneurial nature of ethnic Pakistanis and the kinship/*biradari* networks developed during diaspora led to alternative strategies increasingly being employed.

Perhaps the main difference between the English and Scottish experiences was due to racism (Cleveland Asian Survey 1982; Lawless 1995; Maan 1992; Shaw 2000; Werbner 1990). Whereas ethnic Pakistanis in Scotland continued to be outward looking until the September Events[48], racism had made those dwelling in Riverside much more inward looking much earlier and is mentioned briefly in informants' narratives in the main text.

Many factors militated against good health for South Asians living in Britain. They had lived in the poorer and less well maintained housing stock in the inner city areas. They worked long and often unsocial hours (night shifts in very many cases) and endured racist attacks and racial discrimination. Added to this there was a history of poor nutrition, both in the sending community and during the early days in the UK. The Muslims among them were unable to obtain *halal*[49] meat to eat. Thus they lived on vegetables and chicken, which they were able to buy live and slaughter for themselves in accordance with the requirements of Islam. These factors, at least in the 'race memory' of the state, continue to be perceived as significant in health provision for this minority ethnic group.

When the first members of the pioneer generation arrived in the UK from the sub-continent, many lived in poor material conditions and language was often a problem, especially for the women. They also had illnesses that were novel for the local GP (Hardy 2001, 146-7). By 1991 the various minority ethnic groups in the UK together made up some 6% of the total population. Yet, as many have pointed out[50] their health needs were often not receiving due attention. In this thesis I will add my name to the long list of these who suggest - the NHS could do better.

There are, according to Cauquelin (2000), some common features of South Asian culture and theology. With regard to theology I cannot accept this assertion, for I have found that in the case of Muslims Islam is central to thinking at all points and at all times. Where I strongly agree with Cauquelin is in the area of cultural traits, particularly so in their

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[48] What might best be described as 'Islamophobia' after the terrorist attack on the World Trade Centre and its aftermath (11th September 2001) is discussed separately.
[49] Something that is lawful and permitted in Islam.
[50] Ahmad 1991, 1994, 1996; Hardy 2001; Acheson 1998; Alexander: 1999; Bhopal 1998b; Graham 2000; Green 2003; Helman 1990a, 1990b; Law 1996; Proctor 1992; Townsend 1982.

generosity towards others' beliefs and tolerance when one fails to respect local customs (Cauquelin 2000, 14). This tolerance of the 'other' extends further into many elements of social interaction with 'outsiders' (and here I include myself). For example, the common practice of not criticising the 'other' even when justified, and saying something pleasant instead (Cauquelin 2000, 14). Polite questions are always answered in the positive, even if they do not know the answer to the question. This becomes very relevant when one puts this culture of politeness and positiveness into the contexts of medical encounter.

Malik (2000) discusses Islam and how adherence to this faith impacts on the daily lives of Muslims. Muslims have no problem with Christianity (or any other monotheistic religion for that matter). For them it is the same god – Allah. They recognise all of the major figures revered by Christianity, from Prophet Adam (PBUH) through to Prophet Jesus[51] (PBUH). Muslims believe that Prophet Mohammed (PBUH) is the last of the prophets. As Malik argues the invocation "There is no God but Allah and Muhammad is His Prophet" sums up the religion of Islam (Malik 2000, 97). Malik rightly states that in its original (fundamentalist) form Islam is liberal, humanistic and democratic (Malik 2000, 99), and, having probed beyond the cultural façade often erected by some ethnic Pakistanis, I found this to be the case in all of my encounters with Muslims during my fieldwork. The centrality of Islam to the daily lives of Muslims is often difficult to grasp for non-Muslims. As Lewis has observed:

> 'Modern western man, being unable for the most part to assign a dominant and central place to religion in his own affairs, found himself unable to conceive that any other people in any other place could have done so ... This is reflected in the recurring inability of political, journalistic, and academic commentators alike to recognize the importance of religion in the current affairs of the Muslim world…'
>
> (Lewis, cited in Malik 2000, 103)

[51] *Isa.* See also Appendix 7.

I argue that this is sometimes the case when Health Professionals think of ethnic Pakistanis in Britain today. Also, for many Health Professionals there is a great difficulty in accepting the central importance of Islam. Yet Islam, like other patient-specific data (see below), must be taken into account for these individuals if the medical encounters, such as I shall discuss later, are to be fruitful. And perhaps more importantly, if an effective dialogue is to take place in these encounters between the two sides.

Health Professionals:

Often social science has been critical of Health Professionals (Ahmad 1993, 1994, 1996; Bowler 1994; Foucault 1976; Illich 1995; Oakley 1984; Tassano 1995). One of the most vociferous with regard to issues of ethnic Pakistanis, FCM and thalassaemia has been Ahmad. Ahmad (1996) observes that consanguinity has become cited as the cause of a variety of health problems within the Pakistani and Muslim communities (Ahmad 1996, 83). He argues, with some force, that consanguineous marriage provides an excellent method of victim blaming and allows the NHS absolution from responsibility for issues of inequality and institutional racism (Ahmad 1996, 83). In the process of appearing to be non-racist, by not directly criticising FCM, the NHS shifts responsibility for any birth defects away from Health Professionals and squarely into the hands of those who marry their cousins (Ahmad 1994). In essence the NHS provides non-judgemental information concerning thalassaemia. If the patient then chooses to ignore the risk any blame, for affected births, falls to the parents. The NHS subtext is of a combination of a notion of 'diseased genes' with 'diseased cultures' (Ahmad 1996, 83) that could come from the pages of a far right eugenicist tome. This is becoming more focused with the introduction of national screening programmes and health initiatives.

Power relations, between doctor and patient, are also an area where criticism has been levelled in the past (Bowler 1994; Foucault 1976; Illich 1995; Oakley 1984; Tassano 1995). Bowler (1994, 73), for example, suggested that:

> '...medical power continues to be very strong. Obstetricians are unlikely to give up their control of maternity care, which has increased throughout the twentieth century, without a fight...'

I was told by one lead midwife that the stories of patriarchal medicine were often exaggerated, but conceded that there was a long way to go yet.

Armstrong (1987) suggests that a simple Marxist analysis of the power relations between doctor and patient is too simplistic and takes no account of the taken for granted moments when doctor and patient collude to solve the illness problem. He suggests that a sense of a Foucaultian medical surveillance is at play. The routine medical techniques - questions of enquiry, displaying of the 'injured' body, the stethoscope –are all instruments of power. Yet, for much the same reasons that audit culture is 'logical', we accept that power relationship without question. Yet in both cases these small acts reproduce passivity in the body it surveys (Armstrong cited in Lupton 1994, 111). Lupton (1994) suggests that discipline is here enforced by gratification, rewards and privileges for good conduct. Both doctor and patient subscribe to the necessity and importance of medical tests. Here genetic screening and prenatal testing are implicit, along with constant monitoring and embarrassing procedures – all in the best interest of the patient (Lupton 1994, 112). This surveillance is voluntary; the patient is a willing participant. After all, it is what we have become socialised to expect.

Health Professionals practise this surveillance and inhabit the high moral ground overlaying guilt and punishment on patients who fail or lapse from socially accepted behaviour in regard to their health. Silverman (cited in Lupton 1994, 112) suggests that patients are not 'pounded into submission' but rather 'incited to speak'. There is an invisible power relationship which leads to the patient taking responsibility for their own behaviour. This contains a notion that the patient is being empowered to take control of the medical encounter, but the invisible power structure and surveillance makes a nonsense of this (Lupton 1994, 112).

Doctors are enculturated into this role in the medical encounter via their medical training. Medical training engenders a set of beliefs, systems and procedures on how doctors are to diagnose and interact with patients. One of the elements of this process is the rapid accumulation of 'facts' without too much time being consumed with human communication (Lupton 1994, 117; Ley 1988). Medical students, according to Lupton, are taught that there is a diagnosis and treatment for every condition. This sense of certainty is continued into the further training in the busy hospital setting. The need for quick judgements leads to the patient being viewed as an easily categorised unidimensional stereotype. Spending long periods of time with the patient is not encouraged in the medical setting (Atkinson 1981; Lazarus 1988; Stein 1990; Lupton 1994, 117).

Lupton (1994) suggests that in the past the lay perspective of the health process was somewhat poorly researched, but recent work by historians has brought forth the patient's voice. These studies have demonstrated the power relations that have existed between lay and professional regarding health and illness (Lupton 1994, 104). Furthermore, medical and public health ideologies are incorporated into lay knowledge of health and illness. Lupton does not argue that the general population merely passively absorbs the dominant ideology. Yet many pieces of research simply fail to demonstrate the lay perspective permitting lay respondents to make responses to questions that are socially correct rather than those they know to be true (Lupton 1994, 104). But Lupton notes that some studies revealed a resistance, particularly by working class informants, to official health discourses and a fatalistic view of lifestyle advice claimed, by Health Professionals, to ensure good health (Lupton 1994, 104).

One thing that I have seen often during this research is that Health Professionals are concerned (even fearful in some instances) that they, and their work, are going to be criticised by researchers from the social sciences – as they have so often been over time.[52] I was first aware of this conflict, in a practical sense, during my participation at the Wellcome

[52] Illich - Iatrogenesis, Foucault - the Panopticon (medical gaze), Black, Acheson and Alexander in their reports on the NHS.

Trust postgraduate workshop I attended at Hinxton (2000), where 'hard' science met 'social' science. There the participants, on both sides, were sufficiently secure in their positions that they very often made light of the supposed conflict. This was not the case with several Health Professionals I worked with who were somewhat suspicious of my motives.

I suppose that I am, at times, critical of the Health Professional within this work. Yet the criticisms I level are, in essence, the same ones I have levelled against the educators I have met over the past twenty or so years. That is to say, my expectation was that they would perceive audit as the 'false god' that I had perceived it to be. If I could see this, as a semi-educated working-class northern lad, why could they not? I suggest it is my high expectation, and not criticism, that I am guilty of in this work. One of the first things that I wrestled with in the framing of my research was whether the role of medical anthropology was to give a voice for the patient or to serve as 'handmaiden' to the Health Professional (see Strathern 2000, 140-1). I guess the reader will make final judgement as to how I fit into the continuum. From my perspective, the intention is to give a voice to the members of the ethnic Pakistani side and suggest ways in which Health Professionals can better achieve their aim of delivering better, more effective and non-racist healthcare, in Britain.

Communication, or lack of it, is another area where criticism has been levelled at the health profession in the past and this thesis is also critical of the often poor communication in the medical encounter, in this instance with members of the ethnic Pakistani population in Britain. Parry and Pill (1994) suggested that poor communication was at the root of the failure of health promotion drives to make much impact on their target audiences (Parry & Pill 1994, 7). Parry and Pill also noted that though the patient centred model was seen as the most appropriate, little happened in practice. The model suggests that the Health Professional relinquishes their traditional control of the medical encounter and favours a more equal relationship. Yet Parry and Pill found that this only led to the health profession becoming charged with increasing their control in non-medical areas (Parry & Pill 1994, 17). This trend towards the medical gaze extending into non-medical areas is also carried

forward in the findings of this thesis. Parry and Pill found that Health Professionals and also patients were both resistant to this trend. It was seen as an intrusion into other, non-medical areas of patient's lives. One of the criticisms was that patients wanted to maintain the traditional relationship with their doctor. That is to say the doctor's role was to diagnose and cure disease; lifestyle advice regarding how patients should live their lives was seen as inappropriate (Parry & Pill 1994, 17-8). Some ten years later my research has found that little has changed with regard to the expansion of the medical gaze into the non-medical realm. In addition it has been found, arguably due to the McDonaldization of medicine, that the gap between lay and professional regarding communication in the realm of genetic health is perhaps as wide as it has ever been.

Helman (1990b) counsels Health Professionals that to provide health care for the heterogeneous population in the UK they will have to become applied social scientists in addition to being an applied medical scientist. To do this they will have to take into account their patients' cultural and religious backgrounds which will impact on behaviours in the medical encounter (Helman 1990a, 17; 1990b). Furthermore, there is a mismatch between the lay and professional milieu. Medical school and hospital have set the Health Professional into a distinct sub-culture with all that that implies (Helman 1990b, 19). This subculture then tends to instil in its members a respect for the principles of scientific rationality and an emphasis on measurement and testing. There is also the dualism inherent in modern medicine between mind and body – with the body taking precedence. Thus physical and chemical data have the ascendancy and are seen as more 'real'. This is further reinforced with the increase in technologies, often at the expense of the significance of the patient's cultural background or social class (Helman 1990b, 19).

As Helman and others have frequently suggested, some members of the health professions accordingly reify 'difference' and see the patient as difficult, odd, resistant to treatment or hypochondriacal (also see Ahmad 1994; Proctor 1992), rather than address the hidden culture clash of the various subcultures present at the encounter (Helman 1990b, 22).

Helman continues by suggesting that one cannot necessarily predict the behaviour of a specific group based on knowledge of a few individuals. There is no more a typical Pakistani patient as is there a typical British or European patient. Helman particularly notes the mindset which labels all non-whites as 'immigrant' with all that that implies and do not consider that many such individuals were born in Britain or at the very least have lived and worked in the UK for many, many years (Helman 1990b, 23). This is also one of the key conclusions of this thesis.

Schaffner (1992) suggests that medicine is not simply biology; the doctor/patient is a human interchange like any other. Engelhardt notes that:

> 'One cannot effectively treat patients without attending to their ideas and values. One cannot humanely treat patients without recognizing that their lives are realized within a geography of cultural expectations, of ideas and images of how to live, be ill, suffer, and die.'
>
> (Cited in Schaffner 1992, 311)

Schaffner argues that medicine is not a science and suggests three proofs that this is so (Schaffner 1992, 311-2; also Okasha 2002). The first is that the basic premise of science is the acquisition of knowledge and understanding; meanwhile medicine is the promotion of health and treatment of disease (Okasha 2002, 311). The second point is linked to measures of success. Science is successful when it achieves a true, or approximately true, knowledge; medicine measures success with the prevention or amelioration of disease – the knowledge of how is secondary. Finally, the moral base between the two is vastly different. For science honest reports of experiments and observations are crucial, while medicine is primarily committed to: '...promoting the health of any individual accepted as patient...' (Schaffner 1992, 311-2) – this may well include telling untruths for the patient's 'own good' (Tassano 1995, 33). Schaffner has suggested that medicine can never be replaced by bioscience (Schaffner 1992, 312). This assertion rests on two claims: i) medicine is essentially social; ii) thus it is not reducible to biology in relation to its need for social interaction with the

actors (Schaffner 1992, 312-3; also Pellegrino & Thomasma cited in Schaffner 1992, 312). Medicine is a social interaction between patient and healer and thus can never be reducible to meet the criteria of a science.

Porter cites Frank Wedgwood's apothegm, 'No doubt the final cause of the patient is the doctor' (Porter 1989, 208), and it is arguably still the case today. In Pakistan thalassaemia is not considered an important disorder; there are many causes of infant mortality more pressing and tangible than a rare Mendelian recessive. Most would put illness or death due to thalassaemia major down to 'the Will of Allah'. For that matter so would many other Muslims, who happen to have relatives in Pakistan, in Britain today. The tension comes with modern (Western) allopathic medical models with their need to explain and cure – often despite the patient's wishes or beliefs. In this case Wedgwood's apothegm still holds true – doctor knows best. In the past the Health Professional had no captive audience. More people were sick in the past, and are sick in the developing world, yet they were/are not locked into relations with the medical professionals. This linkage, in contemporary Britain, is due to the rise of state-backed compulsory medical insurance and medical examinations, argues Porter, with I think some justification (Porter 1989, 209). Perhaps this is summed up by a somewhat cynical comment made by Lady Mary Wortley Montagu:

> '…the English [here I would also include ethnic Pakistanis] are easier than any other infatuated by the prospect of universal medicines …we run… after recipes and physicians…' (Porter 1989, 209)

This is even more the case with genetics' ability to delve into the very essence of our being. Molecular biology, or rather the promises made by it, has the medical profession and lay members of the population in its thrall. Thus one specific area of the Health Professional realm that is seen as significant in this research is genetic counselling.

Harper (1998) tells us that most people working in the field of health are familiar with the term genetic counselling and also have some idea of what it means, but it is rarely

defined. For some it is akin to the supportive or psychotherapeutic role that counselling has in the social field. For others it is linked to specialist testing for genetic disease. Yet others see it as a mathematical process for assessing risk and at-risk status. Harper suggests that there is an element of truth in all of these definitions. Harper defines genetic counselling as:

> '...the process by which patients or relatives at risk of a disorder that may be hereditary are advised of the consequences of the disorder, the probability of developing or transmitting it and of the ways in which this may be prevented, avoided or ameliorated.'
>
> (Harper 1998, 3)

A further definition might be:

> 'An educational process that seeks to assist affected and/or at risk individuals to understand the nature of the genetic disorder, its transmission and the options open to them in management and family planning.'
>
> (Harper 1998, 3. See also Lenaghan 1998, 22)

Whatever definition or understanding for the term genetic counsellor one uses the one thing that is seen as most important by the practitioners I have met is that this counselling should, above all else, be nondirective and support the client in their decision, whatever that might be.

According to Harper (1998), many prenatal diagnostic procedures have been developed by, or in close association with, those involved in genetic counselling (Harper 1998, 103). He further suggests that this is why such technologies have been used appropriately and responsibly. However, Harper suggests, with the increase of genetic screening during pregnancy, for example ultrasound and national screening programmes, there are problems related to the lack of counselling of those undergoing these screening processes. Harper argues that this is a potentially harmful trend (Harper 1998, 103). Such technologies should be viewed in the wider context as risk may be assessed, but little real thought has gone into the attitude and wishes of the couple concerned. The majority of

women are unaware of what the screening process is, and many are unaware, until faced with the reality of an affected birth, that they (and their baby) have been screened.

Harper (1998) suggests that for the above reasons the aim should be to discuss prenatal diagnosis before pregnancy occurs. To begin this process during pregnancy is undesirable, yet this is how the NHS most often proceeds. As the norm is for this screening to take place during pregnancy any decisions have to be hurried. This leads to decisions being taken when the women, and their partners, are not in a fit state to make such life and death (sic) decisions.

Williams et al (2004) suggests that nondirective genetic counselling is increasingly problematic, particularly as more and more screening and testing is taking place in the antenatal clinic setting. Williams et al states

> '...Some women are unaware that that they are being screened, and become amazed and shocked if, say, even a small foetal abnormality is seen on the ultrasound scan...'
>
> (Williams et al 2004, 23)

Much genetic counselling involves '..."open" lifestyle choices...', but antenatal counselling, according to Williams et al (ibid), '...usually involves a "closed" or irrevocable decision; whether or not to terminate the pregnancy...' This counselling falls, more and more often, on Health Professionals rather than the limited number of qualified genetic counsellors. Williams et al (2004) suggests that this often leads to a more directive approach being adopted. For example, there is the potential to encourage *best practice* or a desire to support the woman's decision making or perhaps offer options when specifically asked, but what often happens is the subtle (conscious or unconscious) channelling of women down particular pathways for the sake of expedience (ibid). Williams et al (ibid) state that some practitioners had described how the boundaries between choice and coercion had often become blurred. A further problematic issue described by Williams et al (ibid) is the change from explaining certainties to the explaining of probabilities as more and more 'genetic'

tests become common or garden. All of which puts an even greater stress upon effective language and communication issues.

Notions of risk and risk perception:

Perhaps the earliest, significant, anthropological contribution to the discourse of risk was written by Douglas and Wildavsky (1982). This text is primarily concerned with the rise of environmentalism and concentrates on risk perception within that realm. However, there are some generally applicable arguments set out and some insightful comments which are both applicable to my arguments and the wider societal milieu. One of the key arguments put forward by Douglas and Wildavsky is that some dangers are known, whilst others remain unknown and must remain so as no one can know everything – that is to say that '...Most people cannot be aware of most dangers at most times...' (Douglas 1982, 1). This is further compounded when one factors in ethnocentric perspectives of risk, risk perception and risk management. The extent to which risk is perceived ethnocentrically is pivotal to one of the arguments I set forth in this thesis – that is to say the ascribed at-risk status of the ethnic Pakistani side in this encounter. In addition, different people – in this instance Health Professionals and ethic Pakistanis (Muslims in the majority) - worry about different risks, with the first side essentially bounded in the temporal realm, the other side concerned more with a spiritual realm.

One question Douglas raises is, are we more at risk in the present than our forebears were in the past, particularly as life expectancy is increased and that infant mortality rate, discounting the underdeveloped world, has fallen dramatically (Douglas 1982, 2). Douglas (1982) also concerns herself with future risks, in regard to the environment and the environmental debate, and I suggest, along with others (Ahmad 1994; Richards et al 1996; Winston 2003) that the New Genetics may also pose a risk for future generations. Clearly there is a hierarchy of risk, yet there are issues of how that risk is perceived and also on agreement upon the criteria used to rank that risk – risk is culturally constructed (Douglas 1982, 3). This cultural element is crucial in ascertaining which kinds of risk are acceptable

and which are not. Thus risk itself becomes contested and tensions are revealed between the varied cultural constructions overlaid on what, at first sight, would seem to be clear cut and unambiguous (Douglas 1982, 4-5).

Explanations of risk, or perhaps more accurately, apportionment of blame for that risk, is also culturally constructed. Douglas gives the example of blame for illness, in some cultures, being laid at the door of some powerful leader or village elder, yet in others the illness is seen as the just reward for some immoral act of deviant behaviour (Douglas 1982, 7). This is not unlike the general belief, by many Health Professionals, that thalassaemia is merely a genetic mistake or an outmoded adaptation to a long extinct risk and thus should be eradicated by modern medicine. For many members of the other, mainly Muslim, side this same risk is perceived as a test from Allah – even seen, by some, as a way to achieve credit towards paradise. Douglas (1982, 9) suggests that people; '…select their awareness of certain dangers to conform with a specific way of life…'

Douglas suggests that science was once seen as the source of safety, but now science and technology have become perceived as the sources of those very risks (Douglas 1982, 10). In the Age of Modernity science was going to be the saviour of mankind, literally curing all man's ills – and still suggests that long awaited promise with the Human Genome Project and the New Genetics. Yet the postmodern world views science and technology at least as a source of wariness and distrust (Giddens 1991). Also for many people, particularly those with conviction in a deity, their life on Earth is but a brief interlude before eternal life in the 'here-after'. So, for many, science is not even viewed as a threat or risk – but merely something to be endured. Their concerns are in meeting the requirements of their religion and protecting their immortal soul and not their corporeal selves.

Risk is a straightforward consequence of the dangers in a physical situation, but attitudes toward risk are almost entirely experienced at the individual level of perception (Douglas 1982, 193). For Douglas there is also a gap between lay and professional

(scientific) understanding and interpretation of risk. This *risk-gap* needs to be closed, according to the experts:

> '...the lay public must be taught the facts; the scientific message must be clearly labelled...'
>
> (Douglas 1982, 193)

This almost Gradgrindian obsession with the 'facts' has been discussed many times before by more eloquent speakers (Illich 1995; Foucault 1976). I make a small contribution to the debate in what follows here. Douglas identified the tension between objectively calculated risk and subjectively biased individual and group perceptions of risk (Douglas 1982, 194). Douglas further suggests, and I agree, that the predicament is viewed through '...culturally fabricated lenses...' (Douglas 1982, 194), as are often the outcomes reached.

One eloquent example given, by Douglas, of the headlong rush by science blinded to risk by technology toward potential doom was the Titanic:

> '...where the new ability to control most kinds of leaks led to the understocking of lifeboats, the abandonment of safety drills and a disregard of reasonable caution in navigation...'
>
> (Douglas 1992, 196)

I will suggest that this is not too unlike the course set by the health profession in regard to the eradication of a perceived risk, thalassaemia, without due consideration of what this tampering with the genome might risk for future generations. As Douglas suggests:

> '...Shifting risks may be more dangerous than tolerating them, because those who face new risks may be unaccustomed to them and because those who no longer face old ones may become more vulnerable when conditions change...'
>
> (Douglas 1992, 197)

As I said before, Douglas was talking of environmental issues and not specifically the New Genetics, yet her argument could have been written today and be as powerful a warning of future risk as it was over twenty years ago.

When risks are exposed via expert groups, which as Beck (1992) states have become central to the political process, this knowledge has significance. This knowledge is often used against the general population who do not posses this 'expert' knowledge (Wright 1998). Thus a tension grows between those who define risk and those who, due to the lack of knowledge, are forced to become consumers of that defined risk (Beck 1992, 46). Beck argues, and I am inclined to agree, that such risk is often hidden and does not enter the political debate until the damage has been done. One example of this is the race between genetic research and legislation put in place by politicians – more often than not 'fire-fighting' rather than 'fire-prevention'. We recall that Iatrogenesis has long been known as a by-product of twentieth century medicine. Beck (1992) also notes that with the increasing ability of medical science to probe the human body there has been a concomitant increase in the defining of chronic illness (Beck 1992, 204). Beck further notes that these technologies are undertaken even though there are no cures for the disorder, nor all too often are there prospects for such cures. This is even more the case with the use of DNA testing with ever increasing frequency, such as occurs with respect to thalassaemia. The medical profession, in the age of the New Genetics, rather than seeing patients as 'diseased organisms' now has the technology to perceive people at the sub-molecular level via DNA testing. Not only are we flawed in the macro - else why seek medical attention - but we now, quite literally, carry the seed of our own destruction - not to mention that of future generations. Doctors, midwives and to some extent genetic counsellors perceive, for example thalassaemia, from a biomedical standpoint and thus wish to do their utmost to 'cure' the illnesses they perceive.

Castel has suggested the role of government has moved from the control of the dangerous individual to a focus on ways of predicting and preventing undesirable events, for example deviance, physical abnormality and illness (cited in Turner 1995, 226-7). All of these factors are present in the interaction between the two sides studied within this text. Risk has become an all encompassing abstract. The health system has rapidly become a

Foucaultian *Panopticon* where health surveillance and compliance reign supreme. As Castel has put it:

> '...the whole of modem medicine has been engaged in a gradual drift towards the point where the multiplication of systems of health checks makes the individualized interview between practitioner and client almost dispensable. The examination of the patient tends to become the examination of patient records as compiled in various situations by diverse professionals and specialists interconnected solely through the circulation of the individual dossiers...'
>
> (Castel cited in Turner 1995, 227)

Thus the primary aim of the medical gaze is no longer to apprehend individual illness but rather to anticipate all forms of 'danger', whether that danger be medical or social – as is the case regarding FCM within the ethnic Pakistani population in Britain.

A whole new profession has come into being to deal with the overtly politicised notion of risk (Douglas 1982, 10). Risk became, and still is, an academic growth area. Douglas and Wildavsky argue that the public do not perceive risk in the same way as 'experts' and this mismatch between lay and professional perception of risk has created a whole new sub-branch of psychology. The public persist in taking risks in many activities in their daily lives (Douglas 1982, 11) and this arguably remains the case today.

There are many texts which talk about risk and how to assess and manage risk (Viscusi 1998 for example). We as a society have become increasingly risk averse over the post-war period. This has led not only to 'moral panics', which are not new and have probably existed, in some form or another, for as long as the hominids have walked the Earth. However, the difference in the post-war era is the increase in government intervention in the form of legislation and education – a situation that some have described as the 'nanny-state'. This is not too distant from a situation of 'doctor-knows-best' which had predominated, to a greater or lesser extent, for the past two centuries. This combination of a *risk-averse* society, which also maintains an almost blind faith in doctors, despite an almost

constant litany of medical misconduct in the media[53], perpetuates the unequal power relationships between Health Professional and patient. A relationship that arguable adds to risk and influences the processes looked at in this thesis.

Despite this situation Tassano (1995)[54] tells us that never in the history of medicine have doctors been able to help their patients as they are today (also see Porter 1997). Yet patients are more dissatisfied than ever before, as are the doctors that treat them. This argument is not new, Peabody (1881-1927) observed that:

> '...at the very time that medicine was improving, a decline in the physician-patient relationship was taking place...'
>
> (Cited in Porter 1997: 683)

Tassano argues, most cogently, that the reason for this dissatisfaction is the increase in medicine's fealty to the state. This is, arguably, the case in contemporary UK society. I would go further and suggest that audit culture compounds this situation, a culture that I argue also increases risk at many levels by its very processes (sic).

First cousin marriage (FCM) and concerns with consanguinity:

In the original research question consanguinity and the claimed deleterious effects on birth outcome within the ethnic Pakistani side was an important element, but as the research progressed it began to move from that centrality. However, FCM still has an impact on the relationship between the two sides. Health Professionals are said to be particularly concerned with the potential genetic implications of consanguineous unions (Ahmad 1994, 1996; Darr & Modell 1998). Many on the ethnic Pakistani side wish to continue with a traditional marriage pattern, which many claim is encouraged by Islam. For this reason this brief discussion is included here.

Holy suggests that the received wisdom, for anthropologists, is that kinship is the very essence of being human (Holy 1996, 9). Holy agrees with this, in so far as it is taken to

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[53] Serial killers like nurse Beverley Allitt and GP Shipman. Also countless cases of medical negligence and malpractice.

[54] In the Foreword.

mean that some people see themselves being more closely related to some people than others and that this relatedness is based on mutuality, such that this is the base for numerous and varied interactions (ibid). This relatedness, or not, defines roles, rights and often status. As Holy suggests kinship is: '...a difference that makes a difference...' (ibid). However, Holy indicates that the above becomes problematic when one considers the culturally specific reasons for this sense of relatedness. Holy suggests that people often see themselves to be related because of shared '...blood, bone or semen...' (ibid, 10) but also somewhat more obscure conceptions are also very often made to legitimate these kinship linkages. An example used by Holy is shared food which strengthens clan kinship for some groups in New Guinea. There are parallels to be drawn with Muslims, and herein ethnic Pakistanis, where a sense of kinship is drawn from the activity of food sharing as an exemplar of a shared brotherhood or perhaps *biradari.* For example, South Asian food (curry) was used by some of my informants as a trope for a sense of shared kinship or commonality, which was also trans-generational.

Thomas, Durkheim, Van Gennep, and Rivers earlier made it clear that there is an important distinction between physical and social kinship, and that social kinship is not merely an acknowledgement of biology. Thomas (1906) suggested there was a clear distinction between consanguinity and kinship - the former depends on birth, the latter on the law or custom of the community, and this distinction is all-important. Within modern society these are usually the same, though among ethnic Pakistanis in Britain marriage within *biradari* suggests kinship without consanguinity. Holy suggests that modern studies of kinship contain elements of the informant's sense of shared genealogical relationships (Holy 1996, 11), for example a felt sense of genealogical kinship based on a belief of blood relatedness. Without DNA testing all such relations, however strong the evidence may often seem, are in the realm of belief and not fact. Yet such models of biological relatedness are important if kinship is to be isolated analytically from other social interaction (Holy 1996, 12). However, it is consanguinity that is the factor that seems important when looking at

genetics. The Health Professionals are concerned with the biological implications in marital unions rather than any sense of kinship. For this reason I do not see the concept of 'kinship' per se is directly relevant to this research, particularly as much of the anthropological work on kinship has been concerned with non-industrial societies. It may be that many ethnic Pakistanis trace their roots to agricultural labor in the South Asian subcontinent, but for most this is almost mythical. They either journeyed to other countries around the globe or, as is most often the case in my research, were born in the UK and/or raised in Britain – an industrial/post-industrial society. For them, kinship is cousin based or in the network of, most often, fictive aunties and uncles.

Marriage is an important symbolic indicator of one's position within the various organising systems which govern Pakistani daily life both in the UK and in Pakistan. It continues to be an important indicator of a family's *izzat* or social standing for many ethnic Pakistanis and will remain so whilst this population continues to be double-rooted (Werbner 1990). This notion denotes the fact that there is a very real sense for many ethnic Pakistanis in the UK and I guess throughout the world, that their roots are spiritually still in Pakistan, whilst they live and work within the very different milieu of the western world. The preference for endogamous marriage, that is to say within firstly the family or secondly the *biradari*, is still the preferred state of affairs. The preference for cousin marriage has been a tradition in Pakistan since before the Mogul Empire, there is frequent conflation between this tradition and Islam – '...we marry cousins, it's our religion...'. There is however a debate as to whether this practice is increasing or decreasing (Darr & Modell 1988; Shaw 2000). One of the reasons that FCM is said to be increasing is that links between ethnic Pakistanis in the UK and Pakistan have dwindled over recent years, now these links are most often limited to close family. Another related factor is a desire to bring relatives over to the UK to share in the relative prosperity there. This all said, a man may be more easily forgiven by his family for breaking with tradition if his economic worth (to the family) is relatively high (Shaw 2000, 184) - *pragmatic* is perhaps the best single word to describe the

'Pakistanis' I have met both here in the UK and in Pakistan. *Biradari* blood (*Khun*) is passed through the male lineage. Thus it is said that men's sexuality can expand *biradari* but women's sexuality threatens *biradari*[55]. However, for reasons intimated already for this study I propose to limit attention to marriages contracted between first cousins, whether parallel or cross.

There are issues around inbreeding reported within the literature. For example, studies in France and Japan suggested that infant mortality rate (IMR) is double for children whose parents are first cousins compared to children of unrelated parents (van den Berghe 1983, 93). Van den Berghe quotes figures of 17 per 1000 for serious congenital defects from inbred couples; this figure fell to 12 per 1000 for out bred parents. However, van den Berghe concedes that inbreeding depression between first cousins: '…whilst appreciable, is not overwhelming…' (ibid, 95). This is supported by Bittles who cites the Dravidian people of Southern India, who number some 164 million, who have practised FCM for 2,000 years with little sign of high levels of inbreeding depression (Bittles 1983, 103).

Many commentators have suggested that attempts to end cousin marriage on strictly genetic grounds would be problematic. But this apparent 'patient centred approach' – for the commentators are most often medics – holds within it the thought that such unions should be stopped if a way could be found to do so. After all, the couples themselves have no problem with the practice; it is their choice and has been so for many generations.

Ethnic Pakistanis in the UK uphold a tradition of virilocality where the married couple dwell with the groom's parents, at least until the first child is born. Virilocality is the most elegant, and least costly, solution to the problems of paternity confidence and controlling the female's sexuality. The virilocal system goes some way to minimising the cuckolding risk which may divert the male's investment into another's child – a major concern among Pakistani Muslims. The simplest, easiest and cheapest way of policing the wife's sexual activity is the ever watchful eye of the mother-in-law. The groom's mother exercises control over her new daughter-in-law, until at least the first child is born and after

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[55] See Shaw 2000.

which the couple may then move out and start their own home. Even if cuckolding takes place it still keeps the investment within the close kinship group.

Irons argues that when people have trouble acquiring wives in a competitive milieu one common solution has been to give close kinswomen to cousins in exchange for their close kinswomen for marriage (cited in van den Berghe 1983, 108). This practice has resulted in a degree of inbreeding within communities who subscribe to such a solution. Irons argues that the inbreeding is a secondary concern; the acquisition of a wife is paramount in making such a selection. Among ethnic Pakistanis I have had several stories related to me of such solutions with family members who are considered to have had poor marital prospects without this intervention.

Donnan has written extensively on first cousin marriage among Pakistanis (Donnan 1988; 1994) and like many before and since he has concluded that there are no hard and fast rules for FCM when you speak with individuals within groups with links to the sub-continent (Donnan 1988, 208-9). He suggests that '...occupancy of a specific genealogical position might merely be coincidental...' (Donnan 1988, 208). His data, and that of others (Shaw 2000, 144-58), my own included, suggests pragmatic strategies are adopted to meet individual circumstance rather than fixed protocol. The other observation Donnan makes is that anthropology has made linkages between marriage and kinship, without considering the political and economic factors which impact upon such choices.

The preference for first cousin, particularly patrilineal parallel cousin, marriage by many ethnic Pakistanis living in the UK and links to its potentially deleterious affects on birth outcome is a matter of debate by many ethnic Pakistanis and Health Professionals alike. There are problems in establishing consanguinity in the clinical context, as various studies have shown (Darr & Modell 1988; Proctor 1992). Even if the relevant questions are asked there is no certainty that the question will be answered truthfully, for whatever reason (Darr and Modell 1988, 188), or that the answer will shed any light due to the complex

nature of the diaspora.[56] Also statistics that look at anomalies at birth take no account of spontaneous abortion in early pregnancy or congenital defects that are not immediately apparent at birth. Finally, these take no account of differences in consultation patterns or service conditions. All of these factors have a potential impact on the birth outcome.

Darr and Modell suggest that British Pakistanis are a group at '...high genetic risk...' (Darr and Modell 1988, 189), particularly as the population is young and, they say, first cousin marriage is on the increase, leading to an increase in the number of couples at-risk. A further factor is the desire to bring family to the UK to partake in the better general life options available in Britain (again their assertion) – family ties are important within this population. Although Darr and Modell's (1988) research suggests a heightened risk, they were at pains to point out that the social function of FCM is such that to systematically discourage it on genetic grounds '...would certainly do more harm than good...' (Darr and Modell 1988, 189). I shall suggest later that even 'genetic' argument may be flawed.

The frequency of FCM among Pakistanis in Britain has been surveyed by Darr and Modell (1988). In their study of 100 randomly selected British Pakistani mothers in two post-natal wards in West Yorkshire, they suggested that there had been an increase in consanguineous marriage over one generation (Darr & Modell 1988, 186, 189). Again this demonstrates parents wanting to have their children marry into supportive families, which is more likely to happen if they know the person and their family intimately. One of the women questioned during the survey said that she had not told the nurse that her husband was her first cousin: '...because they frown on you and question you if you are married to your cousin...' (Darr and Modell 1988, 188). Darr and Modell argued that migration was a factor in considering cousin marriage, as circles of acquaintance in Pakistan tended to shrink to only the extended family as time passed (1988, 189). Over the past twenty or thirty years more and more time has been devoted to developing relationships and socio-economic linkages in the UK, with less and less time being spent in the home village in Pakistan.

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[56] Family histories of those left in Pakistan may not be known, or only part remembered. Also country of birth questions would give little clue to present situations. (See Ahmad 1994, 425)

Added to this, I suggest, third and fourth generation 'Pakistanis' have little knowledge of the sending community.

The links between poor birth outcome and consanguinity, from the clinical perspective, are somewhat unclear. Some studies make definite links between consanguinity and poor birth outcome (Ahmad 1994, 424, 425) yet data from other research refute these links (Panter-Brick 1991, 1300). There are likely to be small increases in homozygosity in populations that practise consanguineous marriage, but its significance is low and the scope of this study does not allow for any investigation or conclusion[57]. Ahmad suggested that analysis which used social class was also problematic as the Pakistani population in the UK did not neatly fit with the Registrar General's definition, essentially those defined by Goldthorpe (1987). This is compounded by the ascription of women's social class to that of their male 'controller' - be that father or spouse.

It is ten years since Ahmad wrote his article in which he discussed the links between consanguinity and poor birth outcomes, yet much of his argument still remains valid. British ethnic Pakistanis had, and still have, poorer than average perinatal mortality rates (PNMR) and higher than average rates of congenital malformations (See also Hutchesson 1997; Hussain 1998). Ahmad suggested that the whole debate revolved around a fairly strong element of 'blame shifting' (Ahmad 1994, 423). He further argued that it is on 'blame shifting', and not on scientific merit, that the case for a link between consanguineous marriage practices and higher than average rates of congenital defects within the British Pakistani community are based (ibid). Ahmad also suggests that this blame is based on perceptions, by many Health Professionals, that Pakistani marriage patterns are in some way part of a deviant and alien culture, which he says feeds into; '...racist ideas of alienness and deviance...' (Ahmad 1994, 423). I would have to disagree with Ahmad on this, as I have found no evidence that health professionals take this perspective. Quite the contrary, I have

[57] It would require clinical studies, which could amass genetic data sets.

met several who are fully supportive of FCM and have developed strong arguments for its social efficacy and benefits to women.[58]

Ahmad 'lumps together' Pakistanis in no way differently than he accused (white) Health Professionals of doing. Where I would agree with Ahmad would be that institutional racism is a major factor. However, this is for none of the reasons Ahmad has suggested. On the contrary, I will argue that the very attempts at 'non-racist' agendas are at the root of the perpetuation of institutional racism within the UK health care system. Where I further disagree is the linkage of thalassaemia to FCM and poor birth outcome. I strongly suspect that thalassaemia is merely a genetic trope on which the state is attempting to demonstrate its commitment to 'equality of access to health' – which is leading not only to a continuation of institutional racism but also iatrogenesis.

The New Genetics:

According to Weatherall (1985), the first time the concept of New Genetics was coined was in 1979 by David Comings, editor of the *American Journal of Genetics*, when commenting on a paper describing the introduction of a new technological advance in the mapping the human genome. It was noted by Tom Wilkie at the welcome dinner of the Postgraduate Workshop that I attended in 2000, that what we are perhaps now engaged in is the new, New Genetics, such had been the pace of change and innovation regarding genomic research at the turn of the millennium. Weatherall commented that the pace of change was such that he feared that in a few years time we may have:

> '… an extremely valuable technology…without knowing how to use it to the best advantage of our patients; it [would] not be the first time…'
>
> (Weatherall 1985, 1)

I will argue that this may have come to pass in regard to predictive testing of pregnant women, particularly those from minority ethnic groups in Britain today, with the increasing use of 'genetic' screening programmes. There are also very real ethical issues involved with the very process of population and sub-population screening which I also consider.

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[58] The person who developed this position most fully was white, female and very well educated.

The New Genetics signal the birth (sic) of a new kind of medicine, but as Steinberg (1996) rightly argues there are negative implications for the burgeoning science of molecular medicine, particularly for women. The language of the New Genetics is clearly rooted within the biomedical milieu. Steinberg cites Weatherall, who states that: '...it is usually possible to isolate the *offending* gene...' (Steinberg 1996, 259, my emphasis). The gene is growing in currency within the world of science and medicine and has entered popular iconography. The gene can offend or be bad and thus need to be eradicated from the gene pool – with all that that implies. The gene can be mapped, read, [re]written and it has become the universal indicator of reproductive fitness.

Although the rate of change in the field of human genetics has been fast and furious in the past few years from the perspective of science, for most people it has offered little more than the promise of the future development of cures. Although the first small steps have been taken towards the promised gene therapies there have been no new cures for genetic disease. The treatments available for genetic disorders, for example blood transfusion and chelation therapy for sufferers of thalassaemia major, owe almost nothing to the New Genetics, argued Richards and Marteau in the *Troubled Helix* (1996), and there has been very little change since its publication.

Clearly the ethical dimensions of testing are vast. The New Genetics is, as many have argued (Richards & Marteau 1996; Winston 2003), a double edged sword. Much work is still needed to ascertain a balance, and, perhaps more problematic, who decides that balance and in whose interest will that 'balance' favour? For example, will 'disability' and diversity be less tolerated? One of the key debates is whether the new genetics should be used to reduce the incidence of genetic disease within certain groups or whether testing should be used to provide information for informed choice – even if that choice is to do nothing. Are we using the New Genetics as a 'new' form of eugenics, ask Richards and Marteau (Richards & Marteau 1996, 352) – they are far from alone in their concerns.

Many have argued (Lenaghan 1998; Richards & Marteau 1996; Winston 2003) for more education in the New Genetics to allow for informed public debate. Yet, as Richards and Marteau conclude (Richards & Marteau 1996, 352), however educated we become such genetic decisions will still be based on our capacity to imagine possible future relationships, not only for ourselves and our progeny but also for future generations of *Homo Sapiens*. In addition much of that debate will be concerned with Mendelian genetics – knowledge gained by science over a century ago. Yet, as Richards and Marteau argue most potently, this knowledge is not yet part of the common culture (Richards & Marteau 1996, 352).

The language of the New Genetics is perhaps as important as the actual 'science' that it attempts to describe. Pembrey (1996) points out that we 'fight germs', the 'traditional' cause of disease, but how can we 'fight' genetic causes of disease – our genes are the very essence of *us*.

Genetic knowledge brings with it the burden of choice – for example to have an abortion or trust to luck. Pembrey (1996) suggests that 'tinkering' with our genes might well be dangerous, that is put future generations at-risk by these gene-modifications. Pembrey is not alone in his concerns. There are also issues of what affect the information from a test might have on others. For example, what would a partner's reaction be if one were found to be a carrier of a recessive disorder? Should close family members also be informed? These are theoretical issues raised by Pembrey (Pembrey 1996, 76), but they are also real issues in the narratives of individuals that I have talked with during this research.

Pembrey (1996) describes the provision of population testing for common autosomal recessive (Mendelian) diseases as being provided '…in certain areas for some time…' within antenatal clinics (Pembrey 1996, 77) – this is now in all parts of the UK with the introduction of a national screening programme. He further highlights the problems in achieving careful and unhurried decisions if the test comes back positive and suggests that there are moves toward preconception screening. Several informants have also highlighted

these very points to me during my research – indicating that there has been little change in provision since the mid-1990s.

The NHS has traditionally been based on the aim of diagnosis and treatment, but now due to the potential of genetic screening and testing it is beginning to move towards a stronger focus on prevention, that is a 'predict and prevent' model (Lenaghan 1998, 14). One example of this is the setting up of national screening programmes like the one in place for the detection of the haemoglobinopathies in Britain. Critics of this change of focus point out that the technical ability to identify such risks in otherwise healthy individuals should not be interpreted as a justification for such (ibid). Genetic counselling is often advocated in an attempt to make understanding of the implications of test results accessible to the lay population in Britain.

Genetic counselling, genetic testing and the new reproductive technologies:

There has been much debate among health professionals regarding the efficacy and provision of genetic counselling (Pembrey 1996; Richards & Marteau 1996; Lenaghan 1998; Harper 1998) – particularly the cost of such provision. There is also debate as to who should provide such a provision, which continues as I write. All of the literature suggested that the current (at the time the texts were written) provision will be insufficient to meet demand. Again this is still being identified as problematic by my informants. There are those who have suggested that the genetic counselling project should be abandoned and 'genetic tests' should be available for purchase 'over-the-counter'. Fortunately, I have not found this view to be common and none of those I spoke with thought this pathway was desirable.

Lenaghan is not alone in pointing out that the predictive technologies of testing have far outstripped the ability for the majority of people to comprehend or understand the potential impact of such technologies on their lives. Added to this there is more often than not some element of doubt as to the accuracy of genetic tests. Also such tests may well be inconclusive or require professional interpretation. There is also debate as to who should supply this genetic information – trained genetic counsellors or other trained health

professionals such as GPs or nurses? I encountered most of these options during my research.

Education of the public in this context has been much espoused (Richards & Marteau 1996; Lenaghan 1998; Winston 2003), and the main reasons cited for such education are: i) to provide a foundation for counselling, ii) to reduce the cost/need for counselling, and iii) to enable the public to participate in the wider debates about the future development of such technologies (Lenaghan 1998, 124). The House of Commons Select Committee suggested, in 1995, that there was a need for public education on genetics so as to allow them to '...participate and listen intelligently to debate...' (Cited in Lenaghan 1998, 125). My research, and that of many others, suggests that this education has either not taken place or has fallen on deaf ears. This makes the Select Committee's prediction:

> 'The dilemmas that genetics pose will be resolved by the public and parliamentary debate, not by academics alone. But that debate must be well informed, both about the science itself and about its ethical, legal and social implications (House of Commons Select Committee, 1995)'
>
> (Cited in Lenaghan 1998, 125)

Something of a pipedream, I would suggest, at this point in time.

Lenaghan rightly points out that even if such an education process was to take place and also be effective there is no guarantee that rational behaviour would be the outcome. Kahneman and Tversky (1984) suggest that research into public reactions to genetic risk reveal:

> '...irrationality, inconsistency and incompetence in the ways human beings arrive at decisions and choices when faced with uncertainty...'
>
> (Cited in Lenaghan 1998, 124-5)

One only needs to look at the various attempts to penetrate minority ethnic groups in Britain with health education initiatives - whether by the state or via interest groups, for example, the United Kingdom Thalassaemia Society's attempts to highlight risks from thalassaemia

within the population. However, this is somewhat more complex than a simple suggestion that people are irrational - this debate is one of the key threads of this thesis. Parsons (1994) suggests that if parents are aware of the future needs of a child born with a genetic defect they are then often more able to plan for that future in a more positive manner (Parsons 1994, 58). This also suggests that termination is not a desirable outcome for many parents who undergo testing and that the options should be clearly laid out in a nondirective manner, preferably by a trained genetic counsellor, so that all of the options are clear.

The idiot's guide to thalassaemia – here comes the science:

What follows is, I hope, a simple guide to the science of genetics and more specifically the blood disorder thalassaemia – as it affects the ethnic Pakistani side. It is intended to give the reader a base from which to understand what the Health Professionals are talking of in their narratives. One of the issues I consider is how communication becomes problematic between these two sides. I will argue that it is not lack of a common language that is the issue but rather the lack of a common knowledge base that often hampers such communication.[59] What follows is intended to allow the reader preparation for that gap in knowledge.

What is thalassaemia?

Thalassaemia covers a group of genetic blood disorders that are caused by partial or non-production of one of the haemoglobin chains such that the size of red blood cells is significantly reduced. The consequences of this range from a dependence on regular blood transfusions and an elevated risk of high mortality in childhood to mild anaemia (Weatherall & Letsky: 1984 cited in Bradby: 1996, 300-301).

There are two quite separate types of thalassaemia, alpha and beta. Alpha is very prevalent among the ethnic Pakistani population, but very rarely causes problems because of the way it is carried within this population. It would be detected via screening but parents mostly just need to be reassured that it is most frequently not a problem. Furthermore, alpha

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[59] Communication is a two way process (Tx = transmit Rx = receive), both elements must be in place throughout, if either is missing, at any time in the process then communication has failed. Receipt of the message is much more than hearing the sounds made by the other party.

thalassaemia only affects foetuses – they need/use alpha globulin. So, a worst case scenario for alpha would be the foetus dies in the third trimester – that is, stillborn.

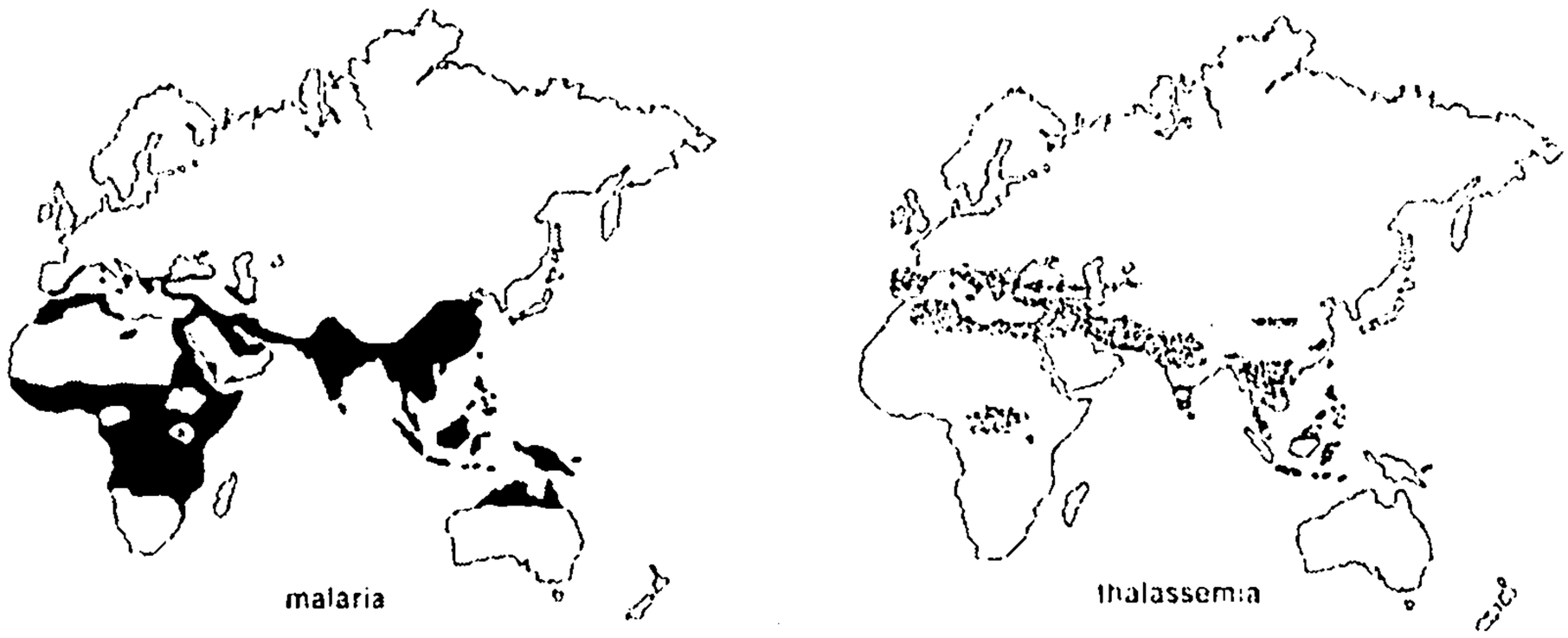
The second type is beta thalassaemia and is the type that this thesis is concerned with as it affects people postpartum. There are seventy variants of this mutation known. It may present as *intermedia* or *major*. It can be treated by bone marrow transplants or by regular blood transfusions, otherwise it can cause severe anaemia, bone defects and problems with the liver and spleen. But transfusions mean that sufferers build up iron in their bodies, which if not removed is fatal. Thus chelation therapy must be undertaken with chelating (iron binding) agents every day for life (See Atkin & Ahmad 2000). The therapy entails having a needle, connected to a pump, inserted for twelve hours a day. As stated above the major form is thankfully rare. There are some 600 cases in Britain, according to the UK Thalassaemia Society.

In a survey looking at the prevalence of alpha thalassaemia in the UK Hassall et al (1998) found that alpha thalassaemia was by far the most common haemoglobinopathy in Britain, but concluded that it was not the cause of serious genetic risk (Hassall et al: 1998, 31). Further, Hassall et al suggests that counselling should focus on the absence of risk (Hassall et al: 1998, 33).

Malaria and the genetics of thalassaemia:

Thalassaemia and sickle cell are the commonest group of genetic disorders in humans. The reason for the strong linkage between the thalassaemia mutation and certain ethnic groups is that carrier status offers protection against malaria (Kwiatkowski 2002; Mange & Mange 1993, 446) due to the formation of smaller blood cells, which have insufficient iron to allow the malaria vector to thrive. It is in the areas of the world that this disease was, or is, endemic that this mutation has the highest penetration (see following map).Thus one of the most effective initial screening methods for this mutation is ascertaining the ethnic (genetic) origin of the individual. Links between malaria and

thalassaemia (and sickle cell anaemia) have been mooted since scientists began to suspect that human evolution had been influenced by malaria in a big way.



(Mange & Mange 1993, 446)

Kwiatkowski (2002) describes the pathway scientists have followed in making discoveries which demonstrated how genetic disorders have evolved by natural selection (http://www.wellcome.ac.uk/malaria/MalariaAndPeople/hbhgen1.html). For example, Haldane thought that if the mutation was inherited from one parent it would give protection to the offspring. Only a few individuals, who inherited the mutation from both parents, would suffer from the lethal form - beta thalassaemia major (http://www.wellcome.ac.uk/malaria/MalariaAndPeople/hbhgen1.html).

Each person has two copies of the relevant gene. These genes, within the South Asian population, are carried in such a way that there can only ever be one deletion (missing gene) – so three possibilities obtain. First, there might be no deletion on either of the parent's allele at this locus (t-t). Secondly, there might be a deletion on just one of the copies, from one of the parents (Tt or tT). Thirdly, there may be a deletion on both copies (TT).

The Punnett Square that illustrates how this combination expresses is shown here:

	T	t
T	T T	T t
t	t T	t t

This gives a 1:4 (TT) chance of Beta thalassaemia major; a 1:4 (tt) chance of no effect; and a 2:4 (Tt or tT) of thalassaemia trait. This risk applies equally to *every* conception.

I have included thc Punnett Square as this was drawn by me on so many occasions when explaining thalassaemia to respondents – usually on the backs of envelopes or scraps of paper. I also used graphic representations of how the mutation is carried and transmitted seem much easier to understand than attempting to write a 'biology essay' to impart the same information.

The numbers of ethnic Pakistanis in Britain carrying the trait is not known with any accuracy. Some put it as high as 15%, others suggest as low as 5%. One of the reasons for this discrepancy may be that if the trait runs in families and they follow the custom of FCM the incidence would appear relatively high within that group – so be at the higher end of the continuum - whilst population screening might yield results at the lower end. The matter of contention, however, is what the level of this 'relatively higher chance' exactly is.

Testing:

Various technical terms are associated with tests to determine whether a fetus is carrying the thalassaemia mutation. Diagnostic tests can indicate if the foetus has a chromosomal abnormality. Some diagnostic tests, amniocentesis[60] and chorionic villus sampling (CVS)[61] for instance, are invasive procedures that carry a risk of miscarriage of around 1% (ARC 2004). Also false positive[62] and false negative[63] are a possibility with these tests. The only certainty is if a full DNA sequencing is undertaken.

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[60] Usually performed around the 16th week of pregnancy. A needle is passed through the woman's abdomen into the uterus, under ultrasound guidance, and a sample of amniotic fluid surrounding the baby is withdrawn. The fluid contains substances from the baby which can be tested for certain conditions. The cells can be tested for chromosomal and inherited disorders (ARC 2004).

[61] This test, which is usually known as CVS, is a prenatal test which can be performed early in pregnancy, from 11 weeks. A sample of tissue that will form the placenta is taken either through the cervix or through the abdomen. (ARC 2004).

[62] Some women are told that tests have shown that their baby may have a problem. If further tests then show that this is not the case, that result is called a false positive.

[63] Some women are told that tests have shown that their baby does not have a particular problem, only to find out when the baby is born that this is not true. This is not a common occurrence.

One specific test for the haemoglobinopathies is haemoglobin electrophoresis. This test measures the different types of haemoglobin in the blood. The test is done when a disorder associated with abnormal forms of hemoglobin (haemoglobinopathy) is suspected.

Screening:

Screening covers non-invasive procedures that are offered to all pregnant women. They are *not* diagnostic. One example of population screening is ultrasound scanning which is a technique used routinely in most hospitals to monitor the growth and development of all babies before birth. Scans before 16 weeks are useful for dating the pregnancy (and are able to detect some major malformations), detailed scanning at 18-21 weeks should show up any major malformations as well as some minor ones.

The National Screening Programme for the Haemoglobinopathies, screening and counselling:

As part of the full blood test undertaken on all British mothers-to-be at their first visit to the antenatal clinic the size of her blood cells is now measured as part of the new national screening project for the haemoglobinopathies. If the cells are below a certain size the partner also has his blood tested to check the size (this varies from 23mu to 28mu, depending on institution/haematologist) of his red blood cells. If his cells are below size then an electrophoresis test is carried out. This simple blood test is the most effective way of detecting thalassaemia (UKTS 2004). Beta thalassaemia carriers are one of the easiest gene disorder carriers to discover, according to the UKTS, as their red blood will be microcytic (smaller in size) and hypochromic (paler in colour).

There is disagreement as to the purpose of screening programmes. One argument is the reduction of the incidence of affected births (through abortion), and it is this criterion that is often used to determine the success of such screening programmes. The other option is to help individuals to take decisions, in essence to terminate the pregnancy or give birth to

the affected child, about their reproductive health. In this second scenario the major area of concern is the provision of non-directive counselling. In essence the medical objective of genetic screening is most often to predict and prevent inherited disease (Bradby 1996, 303). Given that the incidence of thalassaemia (and the other haemoglobinopathies) is highest within the minority ethnic populations in Britain screening programmes often racialise and discriminate against an already vulnerable group and can lead to further discrimination (Bradby 1996, 303). There are also differences between minority ethnic groups with regard to thalassaemic births in Britain. There has been a fall within the Cypriot categories but a rise among ethnic Pakistanis in Britain (BMJ 19/09/1998). There have been suggestions that screening programmes have been ineffective with Britons of South Asian origin due to religion, bad experiences with the NHS and lack of awareness of the mutation (Bradby: 1996, 307). This was no less the case ten years later, as my data will show.

Williamson (cited in Bradby 1996, 308) suggests that individuals are able to assimilate and make choices after non-directive counselling '...with relative ease...'. However, Wilfond and Fost (cited in Bradby 1996, 308) argue that if probabilistic information is given at such counselling sessions they cannot be seen as non-directive. People have difficulty in assimilating statistical data and (see Appendix 1); this is further compounded due to the various pressures inherent in the situation, and as such informed choice is problematic.

Audit Culture:

It has been said that audit culture is arguably the single most invasive and pervasive 'disease' in the modern world. This is no less the case within the health service in Britain.

But what is audit culture? Audit is informed by practice and is not confined to any one institution nor any one part of the world. It is said to be crucial to the credibility of any enterprise in the modern world. As Strathern (2000) rightly notes it evokes a common language of aspiration. Audit causes anxiety and any resistance is seen as deleterious to the

common goal. Audit is very often over demanding and also downright damaging (Strathern 2000, 1).

Audit was in its original sense linked to accountability: an old accounting name it is now a phenomenon which has, in around twenty years, gained a new social presence. Audit is now fecund with demands for an ever expanding plethora of expectations. It mushroomed within the white collar sector but has now also spread its tendrils into all walks of life. As Strathern has so succinctly put it, it has led to '…an almost ubiquitous consensus about aims, objectives and procedures…' (ibid) and has twin passage points which are a meeting of the financial and the moral: economic efficiency and good (best) practice. In audit culture only certain practices count, that is to say only procedures that have been defined count or can be measured or assessed. Innovation and self actualisation are decried as deviant heresy.

Audit then, has now become the descriptor for all sorts of reasonings, evaluations and measurements known as *performance criteria.* These 'measurements' more often than not result in a new series of protocols which must be rigidly adhered to, and are in turn audited. Failure to carry out these rituals results in sanctions – be these real or felt. I shall discuss the enactment of these rituals in relation to my informants and argue that their effect is negative and almost the opposite of the avowed aims and objectives the audit aspires to ensure.

Taken at face value, audit, with its claims of good governance and transparency of operation and which is everywhere endorsed as an outward sign of integrity, offers a global consensus. It is almost impossible to criticise in principle. After all, it advances values of responsibility and openness of outcomes, and it promises widening access. These processes are subject to ritual *external* verification, which in turn impinges in new and important ways. Often fear is the most tangible outcome of the process (Strathern 2000, 1-3). One constant within audit culture is change – by this I mean that the assessment process and goals are very often changed over time. Shore and Wright offer evidence that performance indicators have a short shelf-life (about two years): an inspector admitted, '…after that time people get

wise to them…' (Shore & Wright 2000, 77). Shore and Wright conclude that the intention of audit is to keep people on their toes and perhaps more sinisterly to make them feel insecure and powerless.

Today accountability is taken for granted, a process of neo-liberal government to whose ethos it contributes substantially. This is not seen in day to day direction but rather in internal controls found in the monitoring processes that are now *de rigueur* within institutions in both the private and public sector. Strathern rightly notes that mechanisms have been set up '…where none were before…' (Strathern 2000, 4) with an accompanying rhetoric of '…helping [monitoring] people help [monitor] themselves…' (ibid). This is nothing short of a Foucaultian *Panopticon.* The new practices are more concerned with style and presentation than effectiveness – much along the lines of New Labour's '…seen to be doing…' rather than actually doing.

Furthermore, Strathern suggests that checking only becomes necessary in situations of mistrust, thus audit also has sinister overtones (Strathern 2000, 4). With the government making an explicit requirement for people to check and monitor themselves there is no longer a need for the government to do so – they now only need to check *performance indicators*. The *auditable evidence trail* ensures compliance. Strathern cites Herzfeld's (1992) argument that with audit machinery in place the state avoids accountability for its own action or inaction. Strathern suggests that audit signals epochal change (Strathern 2000, 3). She maintains that rituals of verification are not concerned with content or academic rigour[64] but rather the concern is with the external mechanisms by which such products are valued (Strathern 2000, 279). I suggest that this is little different from that which I describe within the NHS.

Shore and Wright have suggested that audit culture may be seen as a response to the risk society (Shore & Wright 2000, 84-5). They cite Power who posits that audit may be seen as a distinct response of a need to process risk. They also see audit as a '…rapid and relentless spread of coercive technologies…' (Shore & Wright 2000, 57) which have had a

[64] Her anthology is concerned with audit as it impacts on Higher Education.

profound impact on both conditions of work and conditions of thought as '…instruments for new forms of governance and power…' (ibid). This has led to both a new rationality and a new morality which in turn has created new norms of conduct and professional behaviour, whereby professionals are self managing individuals who render themselves auditable.

There is a new *language* to go with audit culture: performance, accreditation, quality assurance, accountability, transparency, efficiency, effectiveness, value for money, bench marking, best practice, peer review, external verification and empowerment, to name but a few. All of these phrases can be found in virtually any government or NGO documentation as standard (for example the Audit Commission 3, cited by Shore and Wright 2000, 60). It is Orwellian 'Newspeak' (Orwell 1954, Appendix). Here are some extracts from *1984*:

> '…while their [words] meanings were far more rigidly defined. All ambiguities and shades of meaning had been purged out of them…' (Orwell 1954, 242)
>
> '…words… were intended to impose a desirable mental attitude upon the person using them…' (Orwell 1954, 244)
>
> 'Some of the B [list] words had highly subtilized meanings, barely intelligible to anyone who had not mastered the language as a whole…' (Orwell 1954, 245)
>
> 'No word in the B vocabulary was ideologically neutral…' (Orwell 1954, 247)

All of which suggest a frighteningly accurate prognostication, if one applies this to audit culture.

One of the effects that Shore and Wright attach to this is that this language is used by government to hide power. Political problems are removed from the political realm and moved into the language of science. We live in a world of league tables and performance charts which often have the effect of 'divide and rule', with individuals complying to protect their individual realm. These external controls have produced an internalisation of new norms – to such an extent that the majority are unable to remember a time when audit was not the norm. As Pollitt puts it, audit culture is '…as unstoppable as virtue itself…' (Pollitt 1993, 49)

Shore and Wright (2000) argue, most cogently, that professionals now conceptualise themselves as depersonalised economic units who are constantly measured and 'enhanced'. Thus people are re-fashioned in their perception of themselves and their work – I have no doubt that a Marxist argument for *alienation* could be easily supported here. Added to this are new categories of 'experts' – quality assurance officers and staff development trainers, for example. Their role is to develop normative grids and classifications for the new frameworks - setting targets and monitoring achievements, judging compliance or ascribing deviance. Another role is to counsel (punish/discipline) deviants and steer individuals to the desired norms (Shore & Wright 2000, 62). Here the 'Ministry of Love' (Orwell 1954, 7) easily springs to mind.

Strathern suggests that, on their own, audit practices seem innocuous and often are perceived as being mundane and inevitable parts of the bureaucratic process. It is only when these small actions are put together to form a larger picture that one is able to see the contours of a distinct cultural artefact (Strathern 2000, 2). Audit culture is concerned with the control of control and not the audited processes. This has also had the effect of creating a culture of compliance, more often than not unquestioning - an outward conformity. I will suggest that this conformity goes much deeper for many individuals that I have talked with during my research. However much people attempt to remain immune to audit rationale it has become a powerful and pervasive technology and, Shore and Wright cogently argue, non-compliance is not an option (Shore & Wright 2000, 76).

Islam and foetal development:

Relevant understandings of Islam will be introduced into this thesis as required, but it may be helpful to review some key notions concerning conception and foetal development. Very often during the fieldwork phase of this research I observed tensions between what was perceived to be tradition and what was claimed as religion, particularly between laymen and the Imam and also between the men and their female relatives. This tension was most often within the male realm. Many older men, and some younger men who

wished to appear knowledgeable when discussing Islam with an 'outsider', often conflated rural traditions, widely held in the sending community, and Islam to prove their point. For this reason it became necessary, for me, to be able to quote chapter and verse from the *Qur'an* or *Hadith* in an attempt to clarify this conflation. I found that the Imam would have the same understandings I had regarding the interpretation of the *Qur'an* with regard to the themes discussed within this thesis, and these were sometimes significantly at odds with the 'rural' Pakistani position. First cousin marriage and abortion were particularly contested areas.

The *Qur'an* is quite clear regarding ensoulment of the foetus and thus calculations can be made regarding permissible abortion and Shari'a Law. However, there has been disagreement and below is described a *fatwa* (ruling on a point of Islamic law) made in an attempt to clarify the Quranic position in this regard. A *fatwa* was made by the President of the High Court of Appeal, in the Yemen Arab Republic, which stated that abortion was allowed under Shari'a law as long as it was done before '...quickening...'; the Shari'a states that this takes place from the beginning of the fifth month of pregnancy (IPPF 1974, 530). This is at least twenty days longer than may be calculated from the *Qur'an*. According to Surah 46:15 and commentary note 4790 (Abdullah Yusuf Ali 1996), a child is weaned at thirty months. From this Muslims are able to calculate the time of ensoulment, when an angel is sent to 'blow the soul' into the child and open the book of that life. This occurs on the one hundred and twentieth day. From that point only Allah may take the soul without sin. Shamsuddin (1974) states that abortion after the ensoulment *(rũh* or 'quickening'*)* is permissible in only one case, that being if the retention of the foetus would put the woman's life at risk. This is acceptable as there is no evidence, in Shari'a law, that a soul should be sacrificed to save another (Shamsuddin 1974, 261). One Iman I spoke with offered further clarification. There were exceptional cases, where there was for example: '...danger to the mother, very dangerous to the mother'. The Imam continued: 'It is better to save the tree than the branches. Like the branch goes away, but the tree is still there. There is another

chance (the mother can become pregnant again in the future). He complicated his point by saying: 'So the child goes away, in certain cases… but if the soul come, the breathing come than that is a difficulty… it is not allowed…Because already god has decided to do that, and soul is there already and breathing…'

So there is no clear, hard and fast rule in Islam. This is one of the reasons that the genetic counsellor (GC) at City General, in Citadel, said that it is often better if the couple can say that the doctor (a powerful figure in this culture) said there should be a termination. In this way the couple deflect any pressure or censure from family and friends and are able to make a free and informed choice whether to continue the pregnancy or not.

I had asked Imam in each research area for their view on the themes flowing through my research, and more crucially how these might be perceived from an Islamic perspective. Often there was a discussion, but always it was made very clear that what I was doing was 'OK' with regard to Islam. In addition, I was told, the research was very much needed at this time. I would be told that the *Qur'an* described everything that modern Western medicine and genctics was finding out. Several *hafiz*[65] had told me that Allah created everything in the world – including the geneticists. It was also said that the *Qur'an* tells us that we should all learn as much as possible – education was a great good and counted towards paradise. I was frequently told that Muslims had a duty to raise healthy children. If something could be done to prevent a child from '…becoming sickly…' then it should be done. Allah had created everything and for that reason how could genetics be wrong?

The *Qur'an* talks of the development of the foetus (Surah 22, 5 Surah 23, 12-14) in three stages.[66] The first stage, which lasts forty days from conception, is *nutfa* – semen (Surah 23, 13). The second stage, which again lasts forty days, is called *alaqa* – blood-like clot (Surah 23, 14). The final stage, again forty days duration, is *mudgha* – lump of flesh (Surah 23, 14). Finally, Surah 23, 14 says:

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[65] Someone who is able to recite the Qur'an, in its entirety, from memory – that is to say knows the Qur'an *by heart*.

[66] Note: The 40 day periods are not given in the Qur'an, but are specified in The *Hadith* of the Prophet. (Musallam: 1983, 54)

'...then We [Allah] made out of that lump bones and clothed the bones with flesh; then We [Allah] developed out of it another creature. So blessed be Allah, The best to create.[67] (Surah 23, 14)[68]

Muslims interpret this final sentence as a direct reference to ensoulment. Quite clearly the above description would be recognised by any biologist or geneticist as an accurate description of the early stages of foetal development. Muslims believe that in revealing the *Qur'an,* Allah: '...spoke to humanity in language it could understand...' (Musallam 1983, 40).

I suggest that abortion, and Islam's position on it[69], is one of the issues that should be pondered by Health Professionals when deciding what options to outline if prenatal screening reveals a potential genetic abnormality. The key question is, at what point of development is the foetus a human being? The answer would be the end of the fourth month after conception, for as noted at this point the foetus is ensouled (Musallam 1983, 40). Anytime before ensoulment the foetus is only '...alive like grass or animals...' (Musallam 1983, 54) so not yet a human being. Thus it is not seen as a sin if, before this point, there is a medical reason to terminate, and the parents agree. So as long as genetic screening and termination are offered within the first trimester there is no problem, from the perspective of Shari'a Law, with abortion. The decision, to terminate or not, was in the hands of the prospective parents. It is thus not a dilemma that is confined to any specific ethnic group.

How does the above link to my research?

I have described the ethnic Pakistani and Health Professionals and given some background to the key concepts I use to open out the issues discussed within this thesis. Some basic knowledge of both Islam and genetics is essential if one is to apprehend the often multi-layered milieu in which these actors operate. Often these factors, which at first appear clear and simple, are used to obscure the real worlds that the players inhabit.

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[67] This has profound consequences for abortion legislation in Islamic Law (Musallam: 1983, 54)
[68] Abdullah Yusuf Ali (1996)*The Meaning of the Holy Qur'an*, pg 846
[69] For a fuller discussion on Islamic attitudes to abortion see Musallam 1983: 57-9 and IPPF (1974) *Islam and Family Planning*, Vol. 2, 4, pg. 259-482

The language of genetics is common place and natural to the Health Professionals who use it in their daily parlance. However, as I hope to demonstrate via the narratives of those involved, this is not always the case for the lay population, whether they are from a minority ethnic group or not. This, added to the pressures of the medical encounter, often makes decision making problematic. This has implications for any sense of informed consent – the consent in this case to abort the potentially 'defective' foetus.

The ability to ascribe at-risk status by one side over the other (specifically Health Professionals over ethnic Pakistanis) has within it many complex issues. Audit culture, I will argue, puts both sides at-risk by its very performance. This in turn leads to an unwitting perpetuation of institutional racism and the related problem of the language myth. Both sides are locked into this position, I will argue, by the imperative to comply with and thus be controlled by audit with its need for auditable evidence trails – trails to which vital funding is attached. In short, both sides are liable to what Wright (1998) has called the politicisation of culture.

Part Two

The Enculturation of Risk

INTRODUCTION TO PART TWO

I suggest that the enculturation process of ethnic Pakistanis in the UK includes, to a greater or lesser extent, a sense of perpetual racial discrimination from the predominantly 'white' ethnic majority. This in turn frames their perceptions of self and 'other' and the interfaces and spaces between. The enculturation process of the other side, Health Professionals, has an inbuilt fear instilled in medical training of an avoidance of appearing to be in any way racist and, I suggest, this drives individuals to demonstrate that this is not the case in their working life. Add to the mix the need, in all walks of life, to provide an auditable evidence trail and you get the current situation where both sides perceive the other as 'other' and both need to exist within the audited world. As time passes more and more auditable evidence is amassed which 'proves' that the enculturated expectations are correct - in reality, a self-fulfilling prophecy. I suggest that this narrow minded approach is the product of the external influence of audit and not racism as such. I also argue that this same audit culture creates non-existent divisions between the minority and majority categories within the UK.

This part of the thesis addresses these matters further. In the following two chapters I will outline some key perceptions, relating to both sides, on risk and on matters of ethnicity and health. These perceptions, and cultural notions that inform them, are clearly central to the thesis. In two further chapters, devoted respectively to Health Professionals and ethnic Pakistanis, I provide some further ethnographic information about the sides in order to help the reader contextualise some of the central issues. I also want to note that in these chapters I introduce an idea, extremely important in ethnic Pakistani identity, of Britishness. The notion of Britishness is crucially an identity that attaches to an individual rather than to a group. Because Britain is a cultural pluralist society everyone who is British has their own cultural preferences which they would want others to respect. But individual choice, not ascribed group membership, determines what these preferences are. Ethnic Pakistanis for example sometimes speak about wanting to be treated the same as everyone else (in Britain). This implies that one can find out about their personal cultural preferences only by asking them as individuals, and not by assuming these preferences by presuming their membership in some crude preordained (ethnic) grouping.

CHAPTER THREE

RISK

Introduction:

As I stated in part one of this thesis, the red thread, my overall argument, revolves around the concept of risk. But what do I mean by risk, how and to whom is there a risk? In this chapter, with reference to my ethnography, I briefly outline some of the themes that I develop during the thesis and try to give a sense of the macro and micro issues that are impacted upon by this concept of risk.

I suggest that there are two main types of risk. The first might be described as physical or actual risk. You jump in front of a speeding train and the risk is that you will be killed. This risk falls into what might be described as one of clear and present danger. The other risk I talk about is perhaps best described as an *imagined* risk. Thus Health Professionals (and politicians) see thalassaemia as a risk to the ethnic Pakistani population. This risk, in the vast majority of cases, is imagined – for in the worst case scenario above 85% of ethnic Pakistanis in Britain are not at-risk from thalassaemia major.

I agree with Shaw that information, whether on risk or any other matter, is not given in a social or cultural vacuum and for this reason I shall describe some of the social milieus of my informants where I feel that it is relevant to my narrative and to those of my informants. However, the overall trajectory of this thesis agrees with and supports Shaw's conclusions (Shaw 2000a, 104) about what she describes as the 'Oxford Pakistani Community' with regard to provisions from the state:

> '...As among non-Pakistanis or 'white' British generally, individuals will take advantages of those aspects of the service which can be accommodated within their current social circumstances and understandings of the world...'
>
> (Shaw 2000a, 104)

A key point of this thesis is to show that state services are strongly influenced by the presumption, with which Shaw seems to agree, that there is a problem in communication in

English for many Pakistanis in the UK. This presumption contributes in a major way to the situation that ethnic Pakistanis are a 'risky group'. I think that this presumption may be false, and I call it a 'language myth'. My view here may paradoxically be more to do with my inabilities and newness to the field rather than any shortcomings of Shaw et al, for in my assertion I believe I speak alone. Shaw (and others) speak 'their[70] language' – I do not. Shaw has written a language course[71] for people who need to interact with the South Asian populations within Britain - which I, among many others, have used. Shaw is multi-lingual and has made friends within what she and others (Ballard 1990, 1994; Maan 1992; Shaw 1989, 1988, 1994, 2000, 2000a; Werbner 1990 et al) have described as the Pakistani community over many years. I on the other hand am not and have only recently entered the field. Thus my Urdu/Panjabi is by the kindest description, according to one of my informants, 'shocking'. For this reason my communication has either been via an interpreter (on occasion during the first couple of months) or in English (the vast majority of conversations). I will argue that this serendipitous state of affairs has afforded me a unique insight into communication with this group of individuals not afforded to Shaw and others simply because of their excellent language skills and time in the field. I talk more about language later in the thesis; at this point, I shall say no more.

Shaw (2000a, 88-9) discusses the models of risk suggested by Giddens (1991) and Beck (1992) to be essentially the difference between on the one hand a traditional, or pre-enlightenment, view of the world where an external force (god/Allah) controls an individual's destiny [preordained/fatalistic], and on the other the modern view based on an individual reflecting on possible risk scenarios, usually linked to information from an 'expert' (in this case a clinician of some sort), and making an informed decision on this information. In the latter case, perception of risk is modified as new data becomes available – again from the 'expert'. I would argue that there is no practical difference in the two processes associated with the two models, nor do I agree that the choice of one over another

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[70] South Asians
[71] *Getting by in Hindi and Urdu* (Shaw 1989).

indicates modernity. In many cases the 'expert' opinion is based on equally questionable data[72]. Thus I question whether medicine can be seen as a science or an art. Put simply, in human progress we all make decisions, or not, on a complex and ever changing set of 'facts', with those given to Muslims being supplied either by the *Qur'an* and *Hadith* or by the stream of letters output from the Human Genome Project, modified by new research or *fatwa.* Pragmatism and superstition are equal motors for human decision making and risk analysis models.

The ethnic Pakistani and Health Professionals' perceptions of risk were quite often at odds. Each side seemed to understand what was being said to them in ways that the other had not expected, or they were surprised at what their words and actions elicited from the other. Each was certain that communication was taking place and that their meanings were being clearly expressed. Quite often any mismatch in communication was missed. I relate some of the conversations I have had to illustrate what I mean. I have also used some of my field-notes from my trip to Pakistan in an attempt to illuminate why I believe the ethnic Pakistani side views the world in a unique way. I have chosen to discuss each side in a separate chapter.

Health Professional views:

Jade, a genetic counsellor from City Hospital in Scotland told me about the physical effects of thalassaemia major:

> '...I'll show you pictures. These are children with beta thalassaemia major... there are many mutations so, that makes a tremendous difference. Children with beta thalassaemia, their bone marrow is obviously making all these red blood cells that are not functioning. The bone marrow is getting desperate because it gets signs [chemical signals from the brain] "You are not making enough red blood cells. You're not making enough red blood cells!" So it starts, there's a bit of a skull [points to picture] and you get this really odd system where all the

[72] No test result is 100% accurate and 'false negative' and 'false positive' are phrases used daily by Health Professionals in sharing test results with their patients.

bone marrow in your mouth starts going [being re-absorbed into the body to help with the increase in red blood cell production] as well. Can you see with this child? [again points to a picture] Because it's trying to make more and more and more red blood cells. What do you do with all these red blood cells that break off? They are being whipped up in the spleen. And this is the spleen right here [again points to a picture] of a little boy from Cyprus. Now you can imagine if people [parents/grandparents] had things like this, and you know they remember that goes into the folk memory. And you know the children stay small, this is a child of four years of age [again a picture of an apparently much younger child is pointed to] but he is small for his age. These are some of the things that go wrong.'

One point that is significant here is that those from a Mediterranean background have experienced a high incidence of thalassaemia major and resultant death of the affected individual, if left untreated. In Pakistan, a much poorer state, these symptoms may go unnoticed as the baby might die prematurely from some other disease. For this reason the 'folk-memory' of thalassaemia would not be as pronounced in this population. Thus education is a significant issue within the ethnic Pakistani population.

Jade explained to me the relationship between malaria and beta thalassaemia:

'...these particular things [mutations] give microcytosis[73] which in the evolutionary terms gave them [the carriers of the mutation] unfavourable conditions for infections from malaria. So, if people were a carrier of beta thalassaemia they had the smaller red blood cells, the malaria bug would invade them but did not get enough iron to really thrive [laughs]. So these babies then got very ill but not so ill that they died. We are talking about new born babies here.

So that people that go back [to the South Asian Sub-continent] now still get extremely ill and still need to take malaria tablets. It's [the thalassaemia

[73] Smaller than average red blood cells.

mutation] not protection [from malaria for adults]. But where, it's a protection... is with the new born baby. There it was a question of life and death. That if you had normal genes like this [pointed to a picture of blood cells of a normal size] without microcytosis, nice big red blood cells and the malaria bug would home in to that and make the baby so ill that it would die, it wouldn't survive. If you were a carrier of beta thalassaemia, that is why it is so very, very common...'

That is why it should not be presented as an illness. She told me she often said to clients:

'Being a carrier, it helps your fore-parents. You wouldn't be here if it wasn't for that.'

All of the minority ethnic community workers within Riverside that I spoke to in the early stages of my research agreed that there was a problem with thalassaemia in the area. They were also quite worried when I said that most of the literature I had read up to that point suggested that thalassaemia was on the increase and was set to continue to grow in the coming years. Indeed Weatherall (1998) and Bittles (1998) had both said, at the 'Ethnicity & Health' conference, that thalassaemia was perhaps the biggest problem facing the world in the 21st century. Freda, one of the education development workers I spoke to in Riverside, and her siblings may well have been suffering from the problems claimed to be related to consanguineous marriage practices. That is to say, I am in little doubt, from Freda's body language reaction to my comments and questions and also her replies, that she herself may have had thalassaemia *intermedia*, and possibly suffered from thalassaemia major - with all that that entails. Talking to women such as Freda I had the first indication of evidence of a generational split on the traditional custom of consanguineous marriage – often on the grounds of 'health'. Yet as my research moved forward a different picture began to emerge.

For example, I was told by Kath, a GSM in Scotland, that very few Pakistani[74] women gave birth in Scotland. I found this odd because I had imagined quite a sizable

[74] The term she used.

population from this group in Scotland. My observations of numbers of South Asians on the streets of Central Scotland had prompted me to broaden my field of research. Yet Health Professionals in Central Scotland seem oblivious to their existence. Perhaps the women give birth at home without accessing the NHS. This seemed unlikely as all of the people that I spoke to used the NHS for the birth of their children. I suspect that people [Health Professionals] have selective memories. Thus if they are not interested in something then they do not remember it. Always there was the suggestion, from Health Professionals working outside Citadel, that I should do my research in Citadel – '…there are lots of them [Pakistanis] there…'

Still in Scotland, according to Jane, a genetic specialist midwife (GSM) (Her role was to support and inform families when there were specific genetic issues either with the pregnancy or a planned pregnancy), very few members of the Pakistani side came through the anti-natal clinic at Jamestown. She was not too sure why that was; perhaps women were pregnant for a second or subsequent time and thus did not feel the need to come to the clinic (as was typical of other ethnic groups). Thus it was suggested that there was little likelihood of my seeing anyone in the process of being counselled for a congenital birth defect. Also a major factor, Jane said, was that community midwives dealt with patients at the booking in process (unlike Integerpool Hospital), where the booking process seems to be done at the hospital and then fed back into the community midwife system). This fitted with remarks about 'bloods' and language needs being 'flagged-up' before the hospital visit. Also there were some 50 midwives involved in the department. For this reason Jane would see only a percentage of patients around the department, and quite a small one, as the likelihood was that 85-95% of the pregnant ethnic Pakistani women would have no genetic problems, at least from the thalassaemia mutation.

At another Scottish hospital I spoke to Dr J, a clinical geneticist, who told me that he did not see significant numbers of ethnic Pakistani couples within his department. This was mainly because his main area of interest was possible genetic linkages with cancer and the

more complex genetic issues. As thalassaemia was a Mendelian recessive disorder, he rarely became involved. He also told me that there were relatively low numbers of ethnic Pakistanis in the Cakestone area. He thought colleagues in London and Birmingham would be seeing larger numbers from this particular group.

Many of the women who Jane sees from the South Asian side seem to be migrants with little command of English. However, there were few patients passing through the system according to both Jane and Kath.[75] This would seem to fit with the low numbers of Pakistani women presenting at the hospital, via this route, due to second/further births. It is also possible that they travel via the haematology route, but this could not be checked as I was unable to gain any information from the Haematologist.[76]

So I had a situation where the 'experts' (e.g. community workers, see p 95) were telling me that there was a major public health problem looming and Health Professionals telling me that there were very few patients from the ethnic Pakistani side coming through either the antenatal clinics or genetics department nor were they aware of anybody in the 'community' with the disease or knew anyone with it. They were told by ethnic Pakistanis: '...certainly not in our family...'. The community workers, as it turned out, had little knowledge of this issue and were just trying to look knowledgeable about *their* community in front of a stranger. Yet there still seemed to be tensions around FCM that were unresolved even with the lack of a visible health problem.

Gill and Modell (1998, 761-2) highlight the differing experiences of thalassaemia in the Cypriot and Pakistani populations in the UK. Whereas the Cypriot population have few, if any, new births of affected children this is not the case within the ethnic Pakistani population. Gill and Modell suggest that this is due mainly to education from the sending community, which is carried forward into population awareness in the UK. Thus Cypriot cases, diagnosed early, generally lead to abortion. They argue there has been little education

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[75] Kath is the GSM at *Poundtown* (Scotland), and is also part of the team put together by Jade.

[76] This was the same person who said that I should 'read a good introductory text on haematology'. When I had done that he would talk to me. This was after I had made it quite clear that I was an anthropologist and not a clinician. I also said I was only interested, at that point in time, in whether the members of the Pakistani community were routed via his team with regard to the haemoglobinopathies.

related to thalassaemia within Pakistan until very recently (Gill & Modell 1998, 761-2). Although screening for carrier status is recommended practice in the UK there has been very little take-up of the service– only 33% of Pakistani couples had prenatal screening (Gill & Modell 1998, 761-2). There is however a 70% take-up rate by couples whose origins are in the South Asian subcontinent who are aware of the disease through education. Modell et al state that current screening practice identifies risk too late in more than half of those at-risk (Modell et al 1997, 782). For this reason it is suggested there is less take-up, by Pakistani couples, particularly if the information about screening is given later in pregnancy. A Royal College of Physicians survey discovered that many areas with large South Asian populations had inadequate screening policies (Gill & Modell 1998, 761-2). For these reasons most new thalassaemic births are from among the British Asian communities (ibid).

As Jade the genetic counsellor (above), states:

> 'My problem is to get couples here, ideally before pregnancy. They have then the choices and we can take DNA and if they both are carriers we say well OK this is the prognosis for your child; a child with thalassaemia intermedia – there may be minor problems to big problems attached to it.'

She explained further:

> 'But if I know that those people are carriers personally [they have been referred for a consultation] in my practice I would take care that this couple get a DNA test, not just some electrophoresis that we do in the lab. It's a more detailed test where we look to see they're not carrying the trait in a bad way.'

Jade described some of the more deleterious aspects of intermedia:

> 'You get some odd things around, right. You also get sometimes a funny way that your legs grow – OK?
>
> 'This is a man of 37 years – who had [thalassaemia] intermedia. He has very heavy pigmentation because of his …

'He also, because of that, would have a damaged spleen so he gets diabetes, he gets sclerosis of the liver, he gets hyperthyroidism and heart problems.

So, it [thalassaemia intermedia] is a huge big thing actually.'

Jade continued:

'I'm going to show you a film. Now this girl is seventeen – look at her bones she is well below average. It is a severe condition [beta thalassaemia major] that really isn't just blood it really will influence your endocrine[77] system and lots of other things.

'And you get a shortening of the upper arms sometimes, because of this. Due to premature bone that is normally growing – it's so busy making bone marrow that it just forgets the bone structure'.

From these brief descriptions of beta thalassaemia one can see that it is a serious illness.

Jade then offered to show me some of the videos that she uses with her clients. These videos, which I discuss in more depth later, give parent's perceptions of the disease and also perspectives from the sufferers and those of the Health Professionals. Health Professionals' views about genetic risk from thalassaemia in the ethnic Pakistani population will inevitably focus on parents who were consanguineously related because of implications of inbreeding. Their attitudes are varied and changing.

Dr J, a clinical geneticist in Scotland, said they did not ask a lot about first cousin marriages – much as was reported by Rachel, a lead midwife in the antenatal clinic in the same hospital. He said that most of the people (South Asians) that he saw were second generation and therefore there were not a lot of first cousin marriages. Dr J said:

'The one thing to say about it is that one in forty children [from the general population] will have a significant congenital malformation or genetic disorder… first cousin marriages doubles that to maybe one in *twenty*... but it's still not a giant risk, over all…'

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[77] Relating to, or denoting glands which secrete hormones or other products directly into the blood

So a senior Health Professional was telling me that genetic risk is low in the ethnic Pakistani population, in Britain – perhaps 95% are not at-risk from this major congenital defect.

I also asked about this 'percentages game' when it came to the giving of information aimed at seeking informed consent. Amun, a third year medical student, said:

> 'Funnily enough on the video [of a Channel 4 documentary looking at the Bristol Heart Enquiry] he was telling us that this difficult operation had a 70% chance of success. But then you always think, you know, especially people who are ill – they always think of the, you know, they want this *hope* that they can latch onto. They think "70%, that's quite high." They can't realise that they might be in the 30% - it's a bit of luck that comes into it - it could be 70%, it could be 30%, you don't know.'

The problem of judging risk from percentages is difficult for doctors as well as patients (see Appendix 1).

Jane, the genetic specialist midwife working in a Scottish maternity unit (above), agreed that risk was a problematic issue in this way. Before this discussion Jane felt that she was doing her best for her patients. The complexities of risk are not generally considered by Health Professionals, for them it is a given. It has been measured, by performance targets being achieved and outcomes met, and in the case of genetics it has been mapped. There is paradoxically a certainty about risk in the measurable and map-able world of modern medicine, but there is little or no time for reflection outwith the performance criteria.

But Health Professionals, by trying to be even handed and give an unbiased stream of information in this, were perhaps sending the wrong message. Or, more accurately, the wrong message is received. Communication is a two-way process and more often than not fails in its attempts. I asked Jane if she thought it might be more in line with the patient centred approach that she should take time to describe the alternatives perhaps more clearly and fully? Jane thought about my question and then replied:

'I hadn't thought of it in that way, what you're saying is explain to them that the outcome predicted by the test leaves some chance of being wrong?'

I said that even a 99% chance of a given risk occurring leaves a 1% chance of the prediction not coming true. What I had suggested was only a slight modification of current practice, the only change was on emphasis. The process of professionalisation and auditable evidence trails 'required' Jane to disclose all of the information, to demonstrate both informed consent and also to cover any possibility of litigation. Jane said that she would keep what we had discussed in mind in the future, but also said that to try to get every single thing in every time was almost impossible to do.

Jane and I talked of differing perceptions of risk from the lay and Health Professional perspective. As we talked I got the sense that Jane had not before considered how the data that she passed on to the patients was perceived. The information was clear to her and the patients said that they understood, and answered questions adequately when 'tested' on retained knowledge. But this did not address patients' perceptions of the meanings of the data imparted. Not only was there a cultural aspect to this understanding of at-risk, (which she and colleagues attempted to address by being aware of ethnicity or apparent educational level), but there were also complex issues of perception and processing surrounding apparently clear and unambiguous information. Herein lies the lay/professional dichotomy regarding perception of risk. For example, an 80% risk seemed quite high (almost certain... in fact...) but carries with it the possibility of a 20% chance of the alternate, and positive, outcome (which may not be appreciated). I suggested that this problem was common to all patients, whatever their ethnic origin. Doctors even share the same misconceptions (see Appendix 1). Which opens the possibility that 'influence' has crept into the equation. Perhaps more specific to ethnic Pakistanis is the Islamic element to the processing of the medical/scientific information imparted. We shall see that, with them, often anything that conflicts with Islam is simply ignored as being false, even by trained (Muslim) doctors.

Ethnic Pakistani views:

Shaw tells us that, in a sense, it is not the genetic risk in life but the certainty of punishment in the next (Shaw 2000a, 88) that informs Muslim perceptions of risk and thus reaction to information on genetic-risk and tests. She refers to the '…hell fires…' so often spoken of by my informants. Shaw tells of an ethnic Pakistani woman who told her that the hell fire flames were hotter than the flames of a gas fire. The gas fire [known] is used to illustrate the concept of the hell fire [unknown] - '…seventy times hotter than a gas fire turned up to maximum' (Shaw 2000a, 88). The use of tropes by Muslims is very common in my experience. The stories and concepts are quite uniform also – always there is a multiplier, a common [known] object or action and a reference to Allah, to add validity to the speaker's argument.

Abdul, an informant from Riverside, said that genetics was a factor when choosing a partner for marriage. Allah had made everyone and everything – including scientists – and he had given men 'free-will' to make choices in their lives. He said the younger generation did not want to marry their cousins because of the risk of having a baby that was sick. If doctors could do tests to see if the baby would be sick and need medicine then you should have them done. He was in favour of screening and prenatal testing. His argument was that you could then make preparations for the baby, if it was going to be '…sickly…'. Clearly Abdul had not considered termination if tests indicated a congenital defect. He, like many other Muslims, would see diagnostic testing as a boon to help make preparation for the birth of the child and its special needs. This view is quite the opposite to the biomedical view of offering termination of a 'defective' foetus.

Mrs Begum, a shopkeeper in North Shore (Riverside), when I asked about congenital birth defects for her part, said there were no such problems in her family, either now or in previous generations. For this reason she would not take it into consideration when selecting a marriage partner when her children got married. She went on to tell me that all such things were in the hands of Allah. She was sure that all of her grandchildren

would be healthy, '…*inshallah*…' Again the common theme that there were no problems in her family was most probably true (as noted, there would seem to be an 85-95% chance of the thalassaemia mutation not being carried), and death in infancy was (is) quite common among South Asians and there is no way of checking cause of death with such infants. Equally *inshallah* is quite literally a way of life for Muslims – it is faith performed.

Shaheen, a young mother for North Shore, was of the opinion that if it was '…their fate…' [to have a baby born with a congenital defect] then it would be so. Shaheen had not heard of genetic testing or genetic counselling being available in Riverside. She said that '…even if it [genetic screening or counselling] existed…' she, and her husband, would not use them. She said if god gave them a child that was sickly then it would be '…the will of Allah… and god doesn't give you more than you can bear…', so they would love it and look after it as best they could – gaining credit towards Paradise. Shaheen, along with most other ethnic Pakistanis I have spoken to, believes that children were a blessing from god and should be treated as such - no matter whether they [the children] are healthy or sickly.

I asked many Muslims, both in England and Scotland, whether abortion would be an option if a doctor said the baby would be born dead or sickly. In one group the older men said that abortion was a sin, so they would not do it. I then explained my understanding of ensoulment and how babies were formed, according to the Qur'an. They seemed to consider this and after a short delay an Imam agreed that I was right about the one hundred and twenty days before the angel '…blew the soul into the foetus…'. He then said that the foetus was '…like cattle or grass before that time …' – not a human being because it had no soul. Only Allah could make a soul so therefore an abortion would not be a sin if it was done before the 120th day. I have little doubt that if I had not mentioned the Qur'an some of the Imam would have remained silent.

The most constant factor in my research has been the centrality of Islam. *Inshallah* to the Muslims I have encountered is not merely a saying, it is an undisputed heartfelt fact. I would like to evidence this assertion via some excerpts from my field notes made whilst I

was in Pakistan. I also suggest that this attitude, so clear in Pakistan, is repeated in Britain and could well exemplify Werbner's notion of doublerootedness.

The ride to Karachi airport from the hotel where I had slept overnight on my arrival in Pakistan and then the internal flight from Karachi to Lahore began my 'education' in risk perception – Pakistan style.

> '…We were all bundled into the mini-bus (very run-down and ill repaired – normal for Pakistan I was to discover) and made a mad dash for the airport. The previous night it had been dark and I was too tired to take much notice of driving etiquette in Pakistan. In broad daylight it became clear that all journeys were in the hands of Allah…'
>
> (Pakistan Field Diary 2000, 8).

The internal flight from Karachi to Lahore further evidenced the differing attitudes to risk in Pakistan compared to that usually associated with the UK. One comment I made in my field diary was:

> '… [the aircraft] was also much older fashioned [than the Boeing 747 from the UK]. For example the seats were bare aluminium struts and somewhat dilapidated. There was no livestock in the cabin – but almost every other conceivable object was. People were milling around and getting into their seats. Finally, everyone was seated and some had even fastened their seatbelts! ... The blessing was played over the PA system and people began to pray. Even more disconcertion the captain said we would be taking off in a few minutes – *inshallah*… I began to feel slightly uneasy as white 'smoke' began to pour out of what seemed at first to be the overhead lockers. Nobody else seemed to be bothered so I began to relax. I decided that it was the air-conditioning fighting the high humidity and temperature…'
>
> (Pakistan Field Diary 2000, 9-10)

I had been used to Western hi-tech well-maintained technology – in the developing world risk is not quite the central issue it is in the 'West.'

When I arrived in Lahore I visited the family[78] of some people I knew from Riverside. When I left the Hussain household I was taken by my new 'brother' to see his friend, a jeweller who lived in another flat just off the Sanda Road. We drank tea and discussed my research – the jeweller spoke fluent English. Again I quote from my diary:

> '…The conversation was quite general, as I had found earlier in the day. The concepts of the 'new genetics' and the genome were not really understood and certainly not part of everyday life in Lahore… [we began to discuss perceptions of risk]. The consensus was *'inshallah'* – god willing - when thinking of risk, either in life in general or birth outcome in particular… All babies were gifts from Allah and if they were in some way 'defective' [my word not theirs] it was seen as a '…test from god…'
>
> (Pakistan Field Diary 2000, 12)

This was absolutely no different to the opinions expressed to me in Britain. I commented on how people drive and cross roads in Lahore and how risky I perceived this to be. They just laughed at me and said I was not used to big city life – it was no different to London (they had both been to Britain to visit family). I said that I believed that

> '…there seemed to be a [very strong] sense of a more fatalistic attitude… in Lahore. They agreed that Allah protects them and if it is their time to die then so be it – "It is the will of Allah." ...'
>
> (Pakistan Field Diary 2000, 12)

As we had driven across Lahore from Toheed Park[79] to Sanda Road[80] I saw my first accident:

> '…we approached the junction, a man [mid-20's?] on a motorbike crossed our path, turned right, and then he and his motorbike went under the wheels of the

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[78] It became clear over the following days that they were also my family.
[79] Their home.
[80] The borrowed flat I was living in.

oncoming lorry – all to the incessant *jii, jii* of the horns of the other drivers. Fortunately, the man was only shaken and got up and pulled his motorbike onto the traffic island – and no doubt started repairs there and then…'

(Pakistan Field Diary 2000, 12)

Nobody stopped or appeared the least bit surprised at the event. The next day I was to gain a practical, and very personal, experience of *inshallah* on a motorbike trip through Lahore, in the rush-hour.

The next morning my 'brother' arrived to take me to meet some of the uncles. First we went to visit an uncle who was a reporter at the *Daily Nawa-I-waqt*. He was not in and would, we were told, return to the office "*Inshallah*." We then remounted the red Honda 125 motorbike and headed into the Lahore traffic. I again quote from my field diary for that day and suggest that it gives a most vivid description of the Pakistani perception of risk. I argue that much the same perspective is performed in relation to genetic risk as is exhibited in daily lifestyle risk:

'…There comes a time when one comes face to face with their own mortality – for me it was on that bike ride through Lahore! In the taxi on the first day I had been encased in metal and [it] felt little different than travelling in the UK. Other journeys had been in *Ricksha* – a motorised tricycle - partially closed in by the cab and having a limited view of the world beyond the driver (aside from the odd donkey's head[81]) – so I had not seen Lahore traffic up-close and personal! The thought struck me that I was perhaps the only person on the road that day that was not [certain that they were] protected by Allah – or at least safe in the absolute knowledge that the worst that could happen to me was [a quick] death followed by [eternal] paradise! One trusts one's fellow man to be able to drive/ride their vehicle – after all they [must] have passed their driving test. I

[81] One day I was travelling into the centre of Lahore in the back of a Ricksha (a motorised tricycle) with the driver, and everyone else on the road, tooting his horn "jii jii, jii jii". We overtook a two wheeled donkey cart on the right. The driver cut the manoeuvre very fine and clipped the donkey. The terrified beast turned its head, which for a brief second appeared inside the Ricksha with me, the look of sheer terror in its eyes was clear to see. It pulled its head out of the Ricksha just in time to avoid decapitation.

found myself weaving through Lahore in the rush-hour riding pillion with a virtual stranger. I was gazing around at the sights of Lahore when suddenly a beautifully painted lorry – with a very jagged front mudguard, just at my knee level – came towards us as we sped along.

I thought Izzy would stop and let the lorry pass – but no – he would overtake the car in front, straight into the path of the beautiful lorry! I remember thinking of the Arab proverb: 'Trust in Allah, but tie up your camels…' just as I pulled my right knee in and avoided the amputation of my lower right limb by the lorry's mudguard! That motorbike ride will be a vivid memory for some years to come…'

(Pakistan Field Diary 2000, 13)

Some ethnic Pakistanis do more directly address the question of the relationship between thalassaemia, FCM and genetic risk. One of the first people I talked to during my UK fieldwork was an ethnic Pakistani community leader in Riverside. When I asked him about thalassaemia he replied:

'…it was always there, only Western [allopathic] medicine and technology makes it known…'

He told me that in Pakistan many children died very young and people did not know the reason. They just saw it as Allah's will and got on with their lives. He said that FCM was common practice in Pakistan, but nobody made the link between that and poor birth outcomes. He said that there was little or no illness as a result of such marriages. He said that there was no evidence in his family, and he was a grandfather, of any sickness and he was married to his cousin. This view was perhaps the most typical I came across throughout my research in three countries.

I spoke to an ethnic Pakistani community development worker in central Scotland about my thoughts around thalassaemia and FCM and asked what she thought. One of the areas that I was keen to investigate was whether genetic testing and genetic counselling

would be useful to families when making arrangements for marriages. She indicated that there was a concern with issues around this topic area, particularly for the younger generations. She said that one area of concern was a significant high incidence of poor birth outcome and genetically inherited disorders within the South Asian population in the area. She told me that there had been advertisements on *Zee TV*[82] where famous *Bollywood* actors and actresses discussed problems with cousin marriage - particularly mentioned was thalassaemia. However, the input from the *Bollywood* actors seemed to be the total extent of knowledge about the subject. Certainly this person, a key information conduit knew no more. What was also clear, from this informant, was that the younger generation, born and raised in the UK, were frequently seen as not being keen on marrying their cousins. According to this informant the risk of thalassaemia or other genetic disorders was now often used to avoid such marriages. She told me that this was particularly apparent when the proposed partner was also from the 'home' village in Pakistan.

I spoke to Julie and Ruksana, two young ethnic Pakistani women at some length. I asked what they knew about thalassaemia and were they concerned about it. Julie said that there were *infomercials*[83] on *Zee TV* about thalassaemia in which '...a few celebrities...' suggest that South Asians should:

'...come in and have a blood test done because thalassaemia is more common in South Asians... a few celebrities asking people to go get a blood test basically...'

Ruksana commented: '...I don't really know much about thalassaemia...' I then explained very briefly what I knew about thalassaemia making the specific point that it was an adaptive mutation that had given protection to their ancestors in the first six months of life from malaria, and in that context it should not be seen as a problem.

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[82] A channel aimed specifically at the South Asian communities in Britain, available via BSkyB satellite.
[83] An information commercial.

Ruksana's comment on my explanation was:

> 'We're not all scientists you know, the, well we erm well we aren't exactly scientists. They [South Asians] don't know what they're getting themselves into, do they?'

I got the sense that even my simple and extremely sketchy outline of what thalassaemia was had been too much for her to understand. Added to this Ruksana did not perceive herself to be a Pakistani woman (she was first a Muslim and then British) – she was conceived in the UK, born in Pakistan and raised from about four months old in Britain - to whom these issues related. Her sense of 'other' when talking about 'Pakistanis' was clear, from both her body language and tone of voice. Ruksana then went on to develop this point about the genetic implications of thalassaemia further:

> '…It's like saying to a smoker, for getting heart disease, "Well that's your fault"…'

There was a strong sense that her attitude was based on experience which had shown her that there were always hidden agendas with regard to health (and health research) for minority ethnic groups. Ruksana's comment points to the very heart of all genetic issues – a sense of being blamed for something that was an accident of birth [sic].

Conclusion:

The general view is that only the ethnic Pakistani population is at risk with regard to thalassaemia. I will suggest that Health Professionals may also in several ways be seen as being at risk by their action or inaction. For example, with devolved budgets there will almost certainly be costs, and concomitant drains on precious resources, attached to their decisions – which may direct a lifetime of blood transfusions and chelation therapy if a child is born with thalassaemia major. Linked to this is the need to meet government targets and league table performance criteria by adhering to *guidelines* and following *best practice*. There is also the sense of failure if such a child is born, for the dominant ideology within the UK healthcare system is the biomedical model with its need to produce the 'standardised'

patient – that is, one free from defect or disease. In the broadest sense these decisions all have an impact on the wider society within the UK. If the finite cake of resources is wasted on people who are ill from birth there is less for everyone else. From the social model of medicine one could count the human costs of such a birth (or abortion of the foetus on medical grounds) rather than dwelling on mere economic factors. I also see the impact of programmes that have the aim of eradicating of certain gene mutations – thalassaemia in this particular instance – being problematic for future generations beyond the current population. There are also often accusations of racism and arguments around ethnic minority access to health. I shall consider these issues more fully in later chapters.

There is a whole raft of ethical and moral issues constructing themselves around the New Genetics which impact on the real world of genetic risk. In this case the risk is more often than not of the variety that I have described as imagined risk. Genes by their very nature are not visible, so even if the test tells us that there is a clear and present danger it is often still not physically manifest. There is also a sense of responsibility involved with this imagined genetic risk – to partners, parents, siblings, children – to assess its magnitude and engage in some form of risk management strategies (Hallowell 1999). Choice and free-will is often the first victim of this imagined risk. There is also a very real possibility that there will be iatrogenic consequences. This may take the form of added worry and stress, invasive prenatal tests or ultimately the eradication from the human genome of a valuable adaptive mutation (Winston 2003). All in all this construction of genetic risk as a moral issue can limit choice – moral and ethical issues are thus conflated into scientific 'fact'.

Measuring and mapping people and highlighting them as being at-risk allows for the possibility of the victim to be blamed for their own misfortune, as has been discussed above – the ultimate self-fulfilling prophecy (Ahmad 1996, 83; Douglas 1986, 56). As noted elsewhere in this text, a woman in North Shore was told her son was at-risk from thalassaemia due to an incestuous union some generations past. This is not too unlike the tradition in Africa, which makes links between leprosy and incest (Douglas 1986, 57) - thus

allowing the support networks, in the African case family and friends, to free themselves from responsibility. This, I would argue, is not too dissimilar to the NHS in the sense that it wants to eradicate the adaptive mutation that causes thalassaemia, and if the victim does not want testing and termination they are made to feel responsible for their child's suffering. If the patient sees that child's sickness as the 'Will of Allah' then the state is able to shift responsibility to the parents for the misfortune (cf. Ahmad 1996, 83). Furthermore, the at-risk status justifies bringing them under medical control; if their child is 'struck down' their rejection of official help explains why they themselves are to blame (cf. Douglas 1986, 57; Deutsch 1982, cited in Douglas).

CHAPTER FOUR

ETHNICITY AND HEALTH

Introduction:

This ethnic Pakistani 'minority group' is far from homogeneous and is filled with 'atypicals' – just like the rest of UK society. Yet commentators [including this one] persist in utilising the concept in their work. The term *South Asian*, which includes people whose roots are in *Bangladesh*, *India* or *Pakistan*, contains within it the suggestion that this group is a homogeneous block. The reality is that even at the most simplistic level the political boundaries created somewhat carelessly by the authors of the decolonisation process of the British Empire after World War Two divide South Asians into various distinct groups (Werbner 1990, xiv). Though boundaries were created as part of the end of the imperial processes the corresponding nationalities and ethnicities, as present in today's Great Britain, are heart-felt by members of these groups – even when the people concerned, and perhaps even their parents, were born and bred outside South Asia itself. As noted earlier most South Asians who came to work in Britain's heavy industries after the war hailed from East and West Pakistan – East Pakistan did not become the independent state of Bangladesh until 1971. To further cloud the demographic picture, there are now 'Pakistani' families from East Africa living throughout Britain. For the purposes of my argument I have tended to use the term *ethnic Pakistani* to describe my informants as this, I feel, best describes one of the sides who populate this thesis – the majority of whom[84] were born in Britain, and as we shall see later, see themselves as *British* despite what the state apparatus would have us believe.

The ethnic Pakistani residents in the UK are in many ways fairly uniform – but there is increasing variation becoming visible. A general description of the ethnic Pakistanis in Northeast England would differ very little from that described by Shaw for Oxford (Shaw 2000, 81-93), or I guess from any other writer on ethnic Pakistanis in the UK (Werbner

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[84] The issues around which this thesis is based require most of the informants to be of childbearing age. So the target group are statistically more likely to have been born in Britain.

1990; Maan 1992; Ballard 1994; Lawless 1995). Pakistanis in North Shore (Riverside) mostly tend to live in the older dwellings – late nineteenth century terraces – in the town centre. The room usage is almost identical to that described by Shaw (2000, 81-85). In the early part of the research I was often restricted to the front room with the ubiquitous pictures of the holy places of Islam, settees and low table, and of course the television, video and computer. Food would be served by a disembodied hand that passed the tray of food or cups of *pakchi*[85] to the man who would set it down and we would eat. Yet exceptions were made. In one couple's home, Razwan and Kausar's, I was invited to enter their family room from day one - the furnishings were much the same, perhaps a little more 'lived-in', but the atmosphere was much more relaxed. I was taken into the family space in several other homes later in the fieldwork.

When I first met Razwan I was with Salina, the CD worker in North Shore. My guess, from their interaction, was that Razwan saw Salina as being his 'fictive' little sister, and as I came with Salina and she treated me as a brother there was no reason for Razwan not to see me also as family [brother] – from day one. I found this unusual and it was many months before I 'cottoned on' to the way Razwan understood our relationship. I do not think it struck me until my experiences in Pakistan. I was aware it was a rather special relationship, but put it down to Razwan and Kausar being atypical – I made notes to that effect in my diary and then ignored it. The reason, apart from the obvious, was that such treatment was so far from my personal experience (or experiences I had read of others in the literature) that I missed it. I thought they were nice people along with the many other nice people I had met in my life. One's experience of family tends to be from birth and taken for granted. I had close relationships with other individuals, but they could better be described relationships of *lena-dena*[86] or patronage rather than that of close family.

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[85] Tea made by boiling the tea and milk with herbs and spices and very sweet, as drunk in Pakistan.
[86] Taking-giving.

Individual Racism and Islamophobia

Individual racism is not central to my argument. However, when it is mentioned by my informants as having a significant impact on their lives it cannot be ignored as a factor in their overall health and well-being. I propose to give briefly some context and relate some of the stories told to me. On the human level racism impacted on people's daily lives. A community development worker who had introduced me to families in Riverside and carried out some translations for me told me what her daughter had said:

> '…Daddy will be alright, he's white, and she [the daughter] would be ok as she looked white. But she was very concerned about her mother and little brother as their skin was dark…'

I returned to visit friends in Riverside in 2003. Razwan told me that their house had been burgled twice and their car burned out, all as a result, they felt, of the September Events. Their eldest daughter Shakira was trapped in her bedroom by the flames from the burning car – Razwan said that if the fire brigade had not come as quickly as they did she would have been killed. One of the burglaries – or perhaps better described as a 'home-invasion' - occurred whilst the family were at home and one of the men held a knife at Razwan's throat and threatened the whole family. Kausar told me that there had also been several incidents of bricks being thrown through their windows. I asked if the police had been called to such serious events. Rizwan said that he had called them but was worried that they might be more trouble. He told me that one day he and his family were just driving out of the end of their road when a police car nearly crashed into them. Razwan said that the policeman rolled down his window and shouted 'Fuck off you black bastard…' Razwan said he was so shocked that he was unable to reply. He said that had it just been someone from the local area it would not have been so bad, he was used to being called a 'black bastard' – what shook him to the very core was that it had been said by a policeman. He was visibly disturbed by the event when recounting the story to me some months afterwards. However, when the police came in the aftermath of the fire he said they were '…very kind

and helpful…' and one of the policemen had taken to inviting himself to tea, which Razwan and Kausar were not unhappy about – it made them feel a little safer in their home.

Another story came to light when I had also asked the community development worker about racism in general in Riverside. This is what she said:

> '…The only racist comments and incidents that I heard [post September 11th] most often related to asylum seekers… the locals became angry and started attacking these families… calling them "black bastard" and "Paki"…'

This evidences how in the eyes of a general population often anyone who is not 'white' is labelled a '*Paki*'[87], conflating 'Pakistanis' and 'asylum seekers' into a general term *Paki*. I suggest that a similar conflation occurs within the NHS. But I will argue that this conflation is not a sign of individual racism, quite the opposite is the case.

This racism is perhaps best described as *Islamophobia* (Runnymede Trust 1997; Shaw 2000, 299; Nielsen 2003 pers. com.) for it is becoming more and more focused on Islam and less and less on ethnicity. The fear of 'Muslim fanatics'[88] wanting to wage *jihad*[89] on the West is generally on the increase in Britain (Shaw 2000, 299). Police in Scotland recorded 2,242 racist incidents in 1999/2000, which was 1,000 more than the year before (Central Research Unit, Scottish Executive). After 'September the 11th' Islamophobia went from a minority group activity to [inter]national obsession.

When I returned to Riverside I spoke with one of my informants who gave me the Muslim perspectives on George W. Bush and the various wars that had happened since we last met. He saw these wars[90] as a series of wars against Islam. He did not agree with suicide bombings against civilian targets but he saw, and from an historical perspective one would have to agree, that it was perhaps the only way for weaker groups to have an affect in the context of the military might of the West (America). He also told me that he believed that in twenty years it would '…come out…' that America was behind 'September 11th' – the

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[87] Perceived in Britain as a racist term used as an insult against someone suspected of being of Pakistani origin.
[88] Usually this term is interchangeable with 'fundamentalist' or 'fundamentalism' in media headlines.
[89] Often translated as 'holy war' but a better, and more accurate, translation would be 'struggle'.
[90] Afghanistan and Iraq being the most significant.

events had just been used by USA to justify attacks on Islamic countries. He suggested that the proof was to be found in there having been no 'weapons of mass destruction' found in Iraq. He also quite justifiably suggested that if the West was serious about getting rid of such weapons it should take the lead. He said:

'Why should they [USA] have them, but nobody else is allowed them?'

This view, he said, was fairly common among other men at his mosque and also in the wider ethnic Pakistani population in the UK. There was also a sense that these external wars were having an impact within the UK and adding to the sense of isolation ethnic Pakistanis felt within the wider British context.

This informant is a very reasonable man, a man who thinks deeply about current issues. It was a discussion with this same man that had resulted in my adding a question about the ethical issues around the use of a genetically modified pig's heart being used for transplant into Muslim patients. When I told him I had discussed his ideas (ethical and moral) about pig's heart transplants with others, he seemed quite pleased that other Muslims had agreed with his analysis of the dilemma. So if he holds particular views of *Weltpolitik* one can assume they are widespread, and that, if anything, they are at the less extreme end of the Islamic spectrum in the UK. He is not a fanatic but a family man like many other ethnic Pakistanis living in the UK. He is fully committed to membership of the wider UK society. Yet the repercussions of '9/11' are impacting on ethnic Pakistanis and forcing them to be increasingly inward looking and as a consequence becoming increasingly resistant to input from 'the outside'. This would include health information – especially any suggestion that the tradition of FCM was putting ethnic Pakistanis at-risk from genetic disorders and should be ceased.

This sense of alienation between Islam and the wider western society – crystallised in the aftermath of the September Events was mentioned in other contexts. For example Julie, a young ethnic Pakistani who was a very level headed and calm individual, reported a

comment made to her by a business woman:

> 'So much of the media and literature is anti-Islam. The west has built it [Islam] up as the true monster of the post-war era. There needs to be a radical change in the attitude of the west.'

This view supporting the perceived existence of Islamophobia is widely held by many Muslims living in the UK.

One of the areas I have tried to unpack in this thesis is the differing understandings of concepts and ideas relating to genetics between lay [in this instance specifically members of the ethnic Pakistani population) and professional. One topic I looked at was the changes that occurred to medical students as they followed their course towards 'doctor-hood'. One student was somewhat surprised how much her views had changed[91] in the three years she was at university. She had increasingly begun to see people as 'other' as her programming progressed. She also felt that at some level she was 'buying into a sense that Muslims/Pakistanis were other' – this she felt was odd as she was herself a Muslim and ethnic Pakistani. I mentioned this to another Muslim student who said, 'Yes, exactly'. She said that the Islamophobia promulgated by George W Bush et al [the West] was causing her to feel increasingly isolated. I said that some of my Muslim informants, in Scotland, were somewhat reticent in talking to me. Amun agreed with my analysis and said that she had noticed there had been an unjustified rise in Islamophobia since '9/11' and she thought that would affect how people interacted with strangers.

I telephone Salina, the community development worker in Riverside, after hearing about attacks on Mosques in Britain after the September Events. She told me:

> '...With regards to September 11th there were small pockets of racist attacks but they soon died down. Amazingly there were no racist incidents reported in Cattleville. None of the mosques were attacked either...
>
> 'A lot of the Muslims in Riverside were disgusted with the events on September 11th. They all hated the fact Bin Laden associated himself to Islam...

[91] The 'heart' and the 'head' were becoming separate realms. And the 'head' [the program] was taking over.

People thought the same with the Iraq war… the Muslims in Riverside also hate Saddam and also feel really embarrassed about the fact that he associates with Islam (cf. Eickelman & Piscatori 1996, 13). The other thing that upsets Muslims in Riverside is the issue relating to suicide bombers, particularly the fact that suicide is prohibited in Islam…'

Most of these people, along with the majority of the UK population, would have no more than a passing interest in wars, but they feel that they are involved because of their religion, or perhaps more accurately others' perceptions and preconceptions of Islam. There was, no doubt, some element of distancing occurring, the men attempting to avoid an anti-Islamic backlash, similar to that reported elsewhere.

The 'Other' and views of the 'Other':

The views of some midwives in England and Scotland are examined here. They are not typical of what I found, but were sufficiently numerous to warrant a mention in the thesis. I am more interested in what it tells us about their perceptions of 'other' rather than subscribing to some form of 'racist witch-hunt' or 'medic-bashing'. I suspect that their upbringing had an impact, but suggest that it is more likely to be part of some form of backlash against *protocols* and *guidelines* set in place to counter charges of 'racism in the NHS'.

A Scottish midwife seemed to conflate 'Pakistanis' and 'asylum seekers' together.[92] I suspect, but have no way of proving, 'patients who can't speak English' have been around longer than the NHS has existed and have always been seen as a problem. Some midwives told me that they had had 'the same problem' with the Chinese '…ten years before...' My take is that there is a perception that 'Muslims all look (dress) the same' and as such are perceived as 'same'. So no one notices when time passes and the ethnic Pakistani women now speak English, with a 'townie' or Scots accent, like the 'indigenous' population, but the next wave of migrants to Britain do not. As noted already, Muslims and Pakistanis are synonymous in many people's minds and thus the language myth rolls on unabated. One

[92] In much the same way as noted above in Riverside.

Kath, a midwife working in Scotland, told me that many of the women she saw were from the:

> 'South Asian community… and all seem to be migrants, with little command of English…'

Yet I have been told time after time '...there aren't many of those here'. I am suggesting that this could then skew the perceptions of the midwives, and for that matter other Health Professionals, into thinking that 'Pakistanis' [still] 'don't speak English'.

There were differing knowledge bases among the midwives that I met over the course of my research. Some were aware of the issues surrounding pollution, for Muslim women, others were not. The same was the case with regard to ensoulment and cultural/religious issues surrounding abortion for Muslims. I did not meet a single midwife involved with the booking-in process who was fully aware of all of these issues in regard to their Muslim clients. Freda, a midwife in Riverside, said:

> 'I think that's because there is so many different [pause] *populations* now there's. [Pause] I mean when I first started my nurse training certainly up in the North East there was very few ethnic minorities around.[93] I mean I actually live in Lungton and we had a couple of Chinese in the Chinese take-away and a couple of Indians[94] in the Indian take-away and that was it. You never saw a black person at all.
>
> 'The first true black person I saw was when I went to London and I was *amazed.* And I think now, you know, with getting so many asylum seekers and things like that there are so many different languages and so many different cultures we [midwives] can't all possibly know everything about them all.'

There are many Health Professionals who are aware of the cultural needs of their clients and who apply that knowledge in assisting them not only with the medical but also

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[93] This is not the case. Freda may not have been aware of them but there has been a significant population of South Asians in the North East for many years. See Lawless (1995) for further discussion of populations, dates and numbers.

[94] It is most likely that the 'Indians' were in reality Pakistanis.

the social aspects surrounding genetic issues. For example, I was told by a Genetic Counsellor that she had found that it was often better for the couple being counselled to be able to say to their family that the Health Professional[95] has said a termination is necessary - if that was the decision they wished to make. As she said, the extended family, who may oppose a termination on *religious* grounds, would not have the burden of having to care for the affected child day in day out, as the couple would. If it is done this way, there can be free informed consent for the couple and any problems with the family can be avoided, or at least minimised. The Health Professional, not the couple, is then 'blamed' for the termination. This understanding of the cultural environment is very important. Her awareness of the 'other' and the cultural milieu which they occupied allowed for her to offer appropriate, and individualised, support.

Others I met were not quite as sympathetic. I suggested to Freda (the midwife above), that as the NHS continues to move towards its target of being more accessible to all its users, its efforts, particularly with regard to giving recognition to minority languages, resulted in a one step forward, two steps back situation. I asked if she felt that by the NHS attempting not to be racist it may become increasingly more institutionally racist. By this I was suggesting that by making an assumption, largely based on the melanin content of a person's skin and the rigid following of protocols, the NHS translates medical information into South Asian languages. Freda commented:

> 'And where do you *stop*, as well, I mean do you, you know, you can keep going and keep going until in the end [long pause] are we going to do everything for all the ethnic minorities. British people, well not even British people, but white people who speak English will be sort of the minority because all the services will be geared towards ethnic minorities and what. I don't know, you know.[96]

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[95] Whether that be the genetic counsellor [if there is one] or the haematologist and obstetrician [if not].

[96] At this point I became mindful of the old adage – 'You could take the woman out of Riverside, but you can't take Riverside out of the woman.' I note Riverside has long had the reputation of being highly racist and the views being expressed here speak to that inherent xenophobia fed by the media images of the 'other'. (See newspaper articles and media stories mentioned elsewhere in the text.) I then attempted to steer the conversation away from this tack and gently suggest that there might be flaws in her 'Sun Reader' mindset.

Clearly her perceptions of the 'other' in this instance seem to be quite negative. But I also think she made a very valid point regarding language and translation – I speak more fully about what I have called the 'language myth' later in the thesis. She said, 'But if you went into their country you would be expected to speak their language.' There was no sense that 'their country' was most likely the UK. In mitigation I sensed that her views were also very much informed by her frustration with the protocols and guidelines within which she had to function.

When I asked questions about special considerations that might be made for a Muslim mum-to-be this midwife was unaware of many simple issues - for example, possible cultural reasons for non-compliance with the procedures in hospital after the birth. I shared the story of a Muslim woman who had tried to wash off the 'polluting' birth blood of her baby. This was caused by current hospital practice of '…putting baby straight onto the mum's tummy…' soon after the birth, to begin the bonding process. I shared other insights but again there was little interest in talking about them or of ways that they might be incorporated into future births that she was involved with.

I asked a third midwife about thalassaemia counselling for couples if diagnostic tests came back positive. She told me that 'Jade (the GC) would deal with such things'. The midwife, who had specialist training in genetics, had said that most (all) of the pregnant women that passed through Poundtown (Scotland) antenatal clinic were not Pakistani (and thus by implication not Muslim), so none of the insights that I had to offer were of interest. She did offer to ask whether any of the other midwives might be interested in talking to me, but she felt that as there were no Pakistanis in Poundtown or the surrounding area there would be no response. My overall sense from this encounter was that audit culture was, for this midwife, a good thing; it allowed for order and stability and my 'looking into corners' might upset the status quo.

Perceptions of Health and Illness:

Health issues, for ethnic Pakistani women, may not be as simple as it might at first seem. One example, of poor eyesight requiring spectacles, demonstrated the very private nature of these issues from an ethnic Pakistani women's point of view. This was the case of Kausar, a young mother whose eyesight was so bad she could not see to drive a car. For a long-time she did not tell her husband Razwan, her mother or anyone of the problem. I was told that ethnic Pakistani women tend not to discuss their health with anyone; they tend to 'suffer in silence'. So it takes little imagination to conclude that more personal health issues – say related to 'women's problems[97]' - would be even more problematic. This suggests that Madhok et al's (1998) work, looking at minority ethnic women's satisfaction with hospital treatment, can largely be dismissed as misleading, and perhaps as putting minority ethnic womens' health at-risk, when they suggested there were no problems to be addressed by the NHS in this regard. It gives a false picture to Health Professionals and managers. If this arguably false image is the one acted upon, then potentially many health problems will go undetected, due to cultural biases and the occlusion of channels of communication.

I also talked with men regarding the health service. One man, in North Shore, told me about his perceptions of the NHS. Although Mohammed mostly sees himself, and his family, as 'Pakistani'[98] - he was very much aware of the implications of Madhok et al's statement with regard to the wider issues of racism. However, he argued that the NHS more than made up for any such problems. The NHS, for Mohammed, was the one thing to outweigh any negative aspects of living in Britain. Mohammed told me that most (if not all) Pakistanis see the NHS as being the best reason for coming to, and staying in, Britain. He further singled out the maternity care as being perhaps the most important aspect of the system.

Mohammed went further and said that the NHS was worth paying for [via taxation] as the alternative, in Pakistan, was no taxes, but no health care either. He told me that it

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[97] That is to say women's sexual health.
[98] He was born in North Shore, as was his wife.

would cost £26,000, in Pakistan, for the anti-natal and post-natal care provided free by the NHS. He said that if he lived 'back there' his children would be sickly. He said most people in Pakistan could not afford such a high price for basic medical care. He told me that, for Muslims, children are seen as perhaps the most important reason for being on earth, after worshiping Allah. Children are a gift from god and it is the duty of parents to have healthy babies and to look after their children to the best of their ability. This attitude supports the contention that the ethnic Pakistani side are very likely to react positively to any NHS initiative or procedure regarding the health of their children. This, Mohammed thought, would be particularly true in the realm of genetic advice, information and testing. Mohammed said to me: '...if yer don't look after the kids yer doin a sin...'

Healthy children are particularly important to Muslims. This view was emphasised by the many Imam I talked with, particularly the *Hafiz*[99] at the Culloden Street mosque in Ironopolis (Riverside), over the past five years. Children have been cited as being central to the lives of all of my informants, of whatever generation or country of birth or domicile, throughout this research. The health of their children is very important and for this reason their interest in supporting my work has been overwhelming.

Mohammed believed that congenital birth defects, in Pakistan, were only due to poverty. Genetics have nothing to do with birth outcome. First cousin marriage (FCM) was also not seen to be a problem, by either Mohammed or Samina, his wife. He told me that the army and police in Pakistan both had healthcare plans. Therefore '...there were no birth defects...' in their families. I said that I had read articles (Grant & Bittles 1997) which suggested linkages between FCM and a high incidence of congenital birth defects in this very group. Mohammed said that was '...rubbish...' - much like '...your Sun newspaper... Just because it was written that did not make it a fact...' Mohammed was very sure of his 'facts' and was not interested in any view that contradicted his own. Furthermore, Mohammed believed that the NHS, in Britain, stopped any risk of birth defects in children from ethnic Pakistani families - along with Allah. Clearly not all ethnic Pakistanis are

[99] Someone who has memorised the *Qur'an* and is also able to recite from the text, without reference.

receptive to information on genetic health, and if they do not agree with genetic explanations then there may be little chance of educating to the contrary.

The sense I gained from my interaction with the ethnic Pakistani side was their almost childlike innocence with regard to illness. This is not meant in a patronising way – I suggest that this side often exhibits an innocence and openness long lost in the wider UK society. For example, one of the many events that I attended was a community development worker's nephew's *hakika.*[100] After the meal, as men were clearing the table, a man, on a table near where I was sitting, had what appeared to be a grand mal seizure. The music was turned off, and after some time the strobe lights were also turned off. Clearly there was little knowledge of the links between flashing lights and epileptic seizures. It was suggested to me that the man had become '…too excited by the evening…' and this was the reason for the fit, not an epileptic seizure brought on by the strobe lights. There was no sense that a medical condition was at work.

The reaction of the guests to the man fitting was very interesting. The whole room ('white' folk not included) came over to look. They were quite unashamedly curious; they had a 'good look' then moved off to let others in. All of this in near total silence. This event put me in mind of the events I had witnessed on the flight out to Pakistan.

A young boy had some kind of fit or seizure on the flight. Nobody, including the PIA cabin staff, seemed to have any idea of what should be done. People, mainly women, seemed at once both shocked and amused, some openly laughing at the boy fitting. After some discussion it seemed to be decided he might benefit from oxygen. The cylinder was brought, but not used. Many people, not necessarily relatives (or so it seemed to me), were given tasks to do: "hold his head", "hold the oxygen", "stand back", "hold valuables"… At intervals people left and rejoined the group, apparently at random. After some 20 minutes the call, 'Is there a doctor on board…' was heard over the PA system. A female doctor, dressed in a *Burqa,* came from the rear of the plane. She spoke briefly to two of the stewards and went forward to where the boy lay. She took one look at him, saw that he was

[100] I was told by the boy's maternal grandfather that this is akin to a Christian christening.

male and said that she could not treat him – even though he appeared very ill. She then returned to her seat at the rear of the plane. A male doctor, an American from the first class compartment, arrived on scene and treated the boy for the remainder of the flight. The boy's parents seemed not to care greatly about their son's well-being. My guess was that they were 'trusting in Allah'. (Taken from field notes on flight to Karachi from Manchester 2000, 5.)

From this it may be seen that perceptions of health and illness are very different from that exhibited by the majority ethnic population in Britain. Ill health initiates curiosity, and what seems noteworthy is the open nature of that curiosity. The other major difference is the unerring trust in Allah shown by Muslims. I comment on this faith many times throughout this thesis. I suspect that it is this faith, and the intertwining of tradition, that gives the best clue to perceptions of the enculturation processes at work with regard to health and illness in this group. What may be perceived as important by Health Professionals may well not be considered to be so by Muslims.

Muslim rituals, NHS rituals – an occasional clash:

Before I went to Pakistan my friend Rauf told me stories of life in Pakistan. One such story concerned what people did when there was a power-cut in the village where he had lived. Rauf told me that there were often power-cuts in Pakistan. When the power went out people would throw stones at the box from which electricity cables flowed from the pole into their homes. They would continue to throw stones at the box until they hit the 'right spot' to 'mend' the broken power supply. The 'right spot' was indicated by the return of the power to their homes. When I was in Lahore I experienced the frequent power-cuts that occurred even in one of Pakistan's largest cities. I was told by a lecturer at a university in Lahore that she had been told that there had been high winds in the desert to the north and that power lines had been blown down. However, whenever the power went down there closely followed the sound of stone upon metal. The people who lived in the block of flats where I stayed came out and threw stones at the power box until they were 'successful' in

affecting the 'repair' to the damaged power supply. I have no proof that the repair to the power lines in the desert, rather than the stoning, made it light in my room again. It all hinges on a belief of how the world works. I suggest that this same world view is at play in the perception of health and illness.

Pertinent here are the stipulations and rituals Muslims must adhere to, the consumption of all clean and wholesome foods. Meat must be *halal,* i.e. of animals killed according to the prescribed method which is similar to the biblical rites. Eating the flesh of pigs, of already dead animals and blood is strictly forbidden (Maan 1992 188). Again these strictures are significant for Muslims in their interactions with the Health Professionals. Purity and pollution are important to Muslims. I was told that the foetus was fed through the umbilical cord so that '...the pollution of the woman [mother] does not infect the mouth of the child – which is used to praise Allah.' By this method the mouth is kept pure for the praise of Allah. From this I took it that Muslims see women *per se* to be unclean – which is little different from similar Christian beliefs.[101]

The ethnic Pakistani perception of woman as second class was raised when I spent some time in a mosque in Scotland. The speaker, a visiting Imam, told us that nothing could be taken into Paradise, '...not even your wife'. This prompted me later in the day to ask the men in the mosque over tea and biscuits what happened to women after death. The *Qur'an* tells us that men will be well looked after by *houris*[102] but what about the women folk? There was a long silence and then I was told that if women were pious they too would be given a 'paradise' also by sharing paradise with their husband. I then asked if this would not cause a problem with the wife and the *houris.* I was told 'The wife would have control and if she forbad the *houris* to approach her husband they would not be allowed to do so. However, there would be 'peace' in paradise, therefore the wife would not argue or object to the husband enjoying the *houris* – if she was pious.' I suggest that this illustrates how

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[101] It is within living memory that '*churching*' was carried out, by the Church of England, on women to purify them after giving birth.
[102] One of the virgin companions of the faithful in the Muslim Paradise

many ethnic Pakistani men perceive Paradise and speaks also to their world view in other matters.

Ethnic Pakistanis pollution beliefs are very important when considering the interaction between the two sides being studied. Defecation and urination are considered to be minor pollutions. Cleansing is by way of running water from a jug (*lota*) using the left hand. More major pollutants are sexual intercourse, menstruation and childbirth, all of which require a complete bath, called *ghusal* (Shaw 2000 87), and much more rigorous ritual cleansing process. The pollution of blood related to the birth of a baby is also perceived as a major pollutant and g*husal* should be performed on the fortieth day after childbirth. The polluting aspect of this blood is significant and the practice, noted earlier, of midwives putting newborn babies onto the mother's abdomen immediately after the birth is considered problematic by most Muslim women.

Many of the women I have spoken to have stated that they want to be treated the same as other women, not as an 'ethnic minority'. However, they want their religious needs to be addressed. I asked Lindy, another Scottish midwife, what current protocols were in place with regard to the period immediately after the birth. I specifically mentioned the current practice of putting the newborn baby directly onto the mother's tummy soon after the birth, before it had been cleaned. Lindy said:

> 'I would argue slightly that it is current practice, in that all women have a birth plan completed at, towards the end of the pregnancy – 36 weeks or thereabouts. And one of the things that we promote or we encourage from the point of view of all the work, the research that has been done into breastfeeding and obviously that's something that we promote because the health benefits of it. That skin-to-skin contact has been shown to be very beneficial getting them off to a good start. So we do encourage skin-to-skin contact as soon as possible after delivery. But we always ask, when completing the birth plan, now for the purposes of skin to skin contact and also the benefits of the baby and

breastfeeding and keeping it warm and regulating the breathing and so forth. So that's what we would encourage: "How do you feel about having your baby delivered onto your tummy? Or would you prefer babies wiped and then given to you?" …you can still, as long as in a reasonable period of time, still have skin-to-skin contact. So I would argue slightly that although we would encourage that we wouldn't the women are given the choice. So they are asked – "Are they happy if that's done?"…'

Here was a clear indication of the defensive nature of NHS staff when faced with questions regarding treatment protocols of patients from minority ethnic groups. I will argue that this very concern and attempts to address it are leading to more, not less ethnic conflict. One can also imagine how an ethnic Pakistani mum-to-be, enculturated to reply positively to a polite question, could be 'encouraged' to have baby 'delivered onto your tummy' rather than be cleansed of pollutants to meet religious belief and custom. It should be noted that Lindy says 'wiped' and not washed, thus some of the blood would remain, the pollution issue would remain. I would also suggest that this has many wider implications for the medical encounter between these two sides.

I talked with several Muslim medical students about pollution, in the Islamic sense, and asked if it had ever been an issue for them, or their family and friends, in interactions with Health Professionals. I explained what I had been told by women in Riverside, regarding the policy of putting newborn babies unwashed onto the mother's tummy. Two of the women agreed that there were issues of pollution in this regard. Tasmin said:

'I remember my mum said when I was born they just handed me over, like to her the way I was and she's just like "Clean her up first please". And she said they were quite surprised because it was like the first child and they didn't think it was a very maternal attitude to say "Clean her up first before you give her to me."

Tasmin's mother is a dentist and well able to hold her own with other Health Professionals. However, retold out of context this story clearly has implications as 'proof' that i] ethnic Pakistani women have 'no maternal instinct', ii] are 'trouble causers' iii] make 'odd requests'. I then related stories I had been told about other Islamic rituals that were also frowned upon by the Health Professional in Riverside. Again both women agreed that they had heard similar stories themselves.

I mentioned the practice of putting the baby directly onto the mother's abdomen after the delivery – to promote bonding and facilitate breast feeding – to a group of men at the Scottish mosque. Abdul said, somewhat angrily:

> 'Look Richard, if your wife and his [one of the mosque's three scholars] wife goes or my wife goes [to hospital to give birth] they will be different because we will be talking about the Islamic point of view…'

I said I understood that, for Muslims, the question, "What is god's will?" is central to all aspects of their lives. However, in this situation (and many other interactions with NHS personnel) there was the strongest likelihood that the midwives and doctors would not be followers of Islam. I explained that it was this interface that I wanted to investigate. At this point Abdul re-introduced the scholar to me, saying that 'he would consult the *Qur'an* and answer all of my questions', and left us to continue the conversation about how the *Qur'an* and *Shari'a Law* impacted on the topics I was researching.

I spoke with Habib, a Muslim medical student at St Andrews, who told me of the rituals that follow the birth for Muslims:

> 'We do the call to the prayer into the child's ear [*Adhan* – the Muslim call to prayer] after the child is born. Not right after birth, but, I think, within a week period [on the seventh day the child is named and its head shaved, and baby boys are also circumcised on the seventh day or later.].

He also described the placing of a sweet into the baby's mouth:

'I think when my father did it in Integerpool Hospital in Cakestone to my niece… The nurse is like "What are you doing?"'

He said that he had to explain to the nurse that it was a religious belief that had to be carried out. Habib continued: '…I think it's quite important…'

I said that I had been told similar stories, by midwives in Riverside, from their perspective the ritual was regarded as a risk to the newborn baby. The placing of a sweet into the baby's mouth was seen by some [non-Muslim] midwives as dangerous; they feared the newborn may choke. Habib said there are millions of Muslims in the world, if this ritual was dangerous and choked newborns '…there would be many less Muslims'. Many of the men I talked with carried out the rituals 'secretly'; that is, when the nurses were not looking.

I said to Habib that one of my concerns, having listened to many stories told to me by informants, was that the NHS spent so much time and effort in translation-related issues that it's missing the essential point – people want to be treated equally in the sense of their dignity and freedom to exercise their right to follow their religion without having to do so out of sight of hospital staff. Habib agreed that this was the case. I suggested that being aware of and taking into account people's religious needs and traditions was far more positive than making assumptions around issues like language. Again Habib agreed that this was a position he could support. In addition Habib said:

'It's true, I mean, like you know like afterbirth there's a different procedure like, like you said like we shave the hair of the head… the nurse might, might not know about it, you know. I think people need to be aware of these things. I mean nurses in general or midwives or whatever… there are a lot of Muslims in this country. And I think a lot of them [Health Professionals] are not very aware of it. …like after the child is born… the call to prayer'

Clearly many Muslims feel that the NHS, at best, fails to take note of their spiritual needs and requirements. On the other hand Health Professionals are concerned that these rituals put the newborn at-risk. This differing perception of risk in the real world is between ethnic

Pakistanis and Health Professionals multiplied many fold when we enter the imagined realm of DNA and genetic mutation.

Problems with interactions between the two sides:

The problems arise when two cultures, Health Professionals and ethnic Pakistanis, collide, and neither fully understands the other's culture. To further complicate matters the players may be unconscious of the enculturation they have undergone and thus be unaware of any problems, as perceived by the other. This 'culture-clash' springs from assumptions and concepts (often hidden) when encountering the other which may well lead to bafflement, irritation or hostility on the part of one or both parties (Helman 1990b, 19). These clashes derive from the enculturation process of the medical school and hospital culture, differing social class, economic status, legal power, gender, doublerootedness, religion or ethnicity.

A behaviour that may well be perceived as rude or aggressive in the UK context is custom and practice in the sending community. I evidence this with several comments taken from my field diary written during my visit to Pakistan. At passport control, at Karachi Airport, I waited my turn – which never seemed to come as everyone pushed in front of me. The 'Americans' (ethnic Pakistanis, one of whom worked at something in genetics at Johns Hopkins Hospital) told me to push on through – I did so reluctantly. I was not comfortable doing so, after all I was a visitor. Much the same story when I tried to organise my overnight accommodation, again my sense of orderly queuing proved futile: I could not get to the counter - others kept pushing in. I began to push, a habit that I would quickly learn and would become second nature within days. The next morning refreshed I decided it was time to 'get with the programme'. I was not happy with being 'rude' to people I did not even know – but there seemed to be no other way to get by in a country that has no word for 'please' (Pakistan field diary 2000).

In the airport I had to have my bag sealed with a green plastic band. I pushed my way to the front of the queue and held off the throng until the official had sealed my pack. I

had learned very quickly that if I was too passive I would be there all day. Next check-in, there was no clear indication which counter was the one to use. Neither was there an orderly queue to join. I pushed my way to the counter and thrust my pack on the weighing machine and presented my ticket – I had learned 'good manners' or at least developed effective social skills - Pakistan-style. Within twelve hours of arrival, in Pakistan, I had begun to function in a manner that was socially acceptable within the culture in which I found myself.

I suggest that it is this set of social norms that very often governs interactions, especially among ethnic Pakistanis in the older generation, living in Britain. Moreover, 'youngsters' are enculturated in this manner in the home and in the mosque. There is no malice or rudeness intended by these actions, although suspicion is that the Health Professionals faced with these actions often take offence at the apparent rudeness displayed by ethnic Pakistani patients and their families. I have on many occasions observed the eating practices of ethnic Pakistanis, both in the home and in the mosque, where people (the men to be more precise) eat very quickly. My guess is that as meals are eaten very often from communal bowls (a sign of brotherhood within Islam), if you're not quick you go hungry. Yet these individuals are some of the kindest and most generous that I have ever encountered.

I was invited to a feminist history colloquium – *Riverside Through Women's Eyes* – at a local university. The main speaker at this event was Tazneem Khan, a woman who briefly taught me Urdu, who told the audience that most of the ethnic Pakistani children in Riverside were born in hospital. Tazneem also told the audience of how nobody wanted to listen to their requests regarding their religious and dietary needs in the NHS. One of the biggest scandals from the early days of the diaspora, she said, was of the Health Professional's complicity in letting children do translations for their parents. Tazneem continued to tell the group of mainly white academics about the 'Myth of Return' and how for many of the older generation it is still the dream – often only achieved in death. What I

found to be significant was that there was no mention, throughout Tazneem's paper, of any language problems in contemporary interactions between the two sides.

Another ethnic Pakistani community worker that I met, Shaheen, said that the general perception she had about access to health care in Riverside was that '…South Asian women get a lower standard of care than the others [white women]…' from the Health Professionals. She thought that the general attitude to women, by GPs, was magnified for South Asian women. The belief is that women are imagining illness or are in some way exaggerating the pain or discomfort suffered. Shaheen said that her view was that the attitudes of GPs were even worse in the case of those GPs of South Asian origin. The specific GP named had come up in conversation many, many times before and since – in conversations with members of all ethnic groups. But I have the sense that the South Asian women's expectations from a South Asian doctor were greater. After all '…they [South Asian GPs] know about our culture and religion…' had often been remarked to me over the course of the research.

I talked to community workers in other areas of Riverside also. The consensus of the women that I talked to during a visit to the Standaira education centre agreed that institutional racism in the health service was a fact. They had told me of their observations of the process, whilst attending clinics with friends or family or some of the women from the local area. Their perception was that the Health Professionals assumed there was a need to speak slowly, as if to a small child, as Shafiul stated. The mainstay of their evidence was that it was assumed, by the Health Professionals, that this would be necessary for communication to take place. They also confirmed that Asian women tend not to go to the doctor, for cultural reasons. By this I understood them to mean that women did not share their illness – as noted above - even with close family, so going to a doctor would be problematic. (This however should be juxtaposed against several women who told me they 'booked-in' for the full ten days in hospital after the birth of a child, to get a rest from household chores and the other children.) These reasons were ranged around *Shari'a Law* –

I was told that the women felt they should only be seen by female doctors. As most of the doctors in the two GP practices in North Shore are male this makes it difficult for women to seek medical treatment.

Another factor was that women's sexual health issues are held to be *plit*, or polluted, and are thus not for public discussion. There was a strong sense that if a South Asian woman goes to the doctor with sexual health issues there is great potential for cultural harm to be done and potentially great shame brought on herself and her family. There was also a sense that if a woman talked to a South Asian doctor about their health it may result in the doctor breaching patient confidentiality and discussing the patient's personal matters with their family. There was a belief that the cultural milieu within the South Asian population was much stronger than the Hippocratic Oath in these matters. Also the women said that 'Western' doctors tend to think that Asian women were always complaining. Freda (who had been a translator for the local health service) told me a story about an Asian woman who was a little slow in getting undressed and the doctor told her to '... hurry up!..'. There was a general consensus, among the women I talked to at the Standaira, that Health Professionals perceive South Asian women to be generally slow.

I had been told of one particular South Asian GP who practised in North Shore who always refused to communicate with his South Asian patients other than in English. There is also strong evidence from my experiences that shyness, rather than lack of competence, was often the reason many women claimed not to speak English. This GP was an ethnic Pakistani himself, and would be well aware of the language abilities of his patients, especially in such a close-knit realm as that of North Shore. The Asian Survey (CCRI 1982a, 19) reported that husbands often had to take time off work to accompany and translate for their wives. I would argue, from my knowledge of the ethnic Pakistanis that the men, being, in the majority Muslims, did not trust their wives to be alone with another male, and this was the most likely factor in this choice, not language difficulties. Oddly enough the same survey states fifteen respondents mentioned they had an Asian doctor who spoke

their own language (ibid). One notes that the majority of doctors (ten out of thirteen) in the two practices in North Shore were of South Asian origin. On a much more important issue – females being treated by female doctors – according to the survey the majority of both women and their husbands were happy for the women to receive treatment from a male GP (CCRI 1982a, 19).

The health experiences of one of the students I taught, Ghulwant, who had recently moved to Riverside (England) from Citadel (Scotland), was particularly instrumental in setting the eventual trajectory that this thesis had taken. Ghulwant was unwell, the symptoms she described were similar to anaemia, but she confided that she was having difficulties in getting the necessary diagnosis and support from her ('white') GP. Almost weekly she would tell me of the events ranging from lack of interest in her ailments to out and out hostility from her GP. Ghulwant told me that the doctor had said to her that she was:

> '…wasting his time by attending his surgery so often… there was nothing wrong with her…'

Eventually she sought private medical analysis, via the alternative medical pathway, from a holistic practitioner and was diagnosed by him as having thalassaemia. I know this second doctor (who was white) trained in the South Asian subcontinent, which is probably why he was more 'on-the-ball' than his NHS counterpart.

Ghulwant said he was the only one to take her complaints seriously and offer a treatment regime to alleviate the condition. She was unable to continue to see the holistic doctor, as he 'cost too much'. Shortly after completing her education course Ghulwant and her family returned to Citadel to live. One reason she gave was that she felt that the health care in Citadel, for her condition, was much better. The second reason was the high level of racism in Riverside, which she was not used to. She felt that Riverside was a bad place to bring up her family and 'voted with her feet' as soon as the opportunity arose.

Anastasia, an ethnic Pakistani student, told me: 'My dad's… had some [health] problems…' He had a consultation with a specialist, but not the one he normally saw, and

'...the guy [specialist] really treated him differently....' Or that is how her father perceived it. Anastasia continued: '...Dad felt he treated him differently... like he didn't know anything...' The doctor did not have her father's medical records and '...wouldn't give him all the tests that he required...' So she said her father flew to Pakistan and had all these tests done there. Anastasia's cousin was a doctor in Pakistan and '...he got all of the tests done straightaway...' He then brought the results back to the UK and said: '... "Look, this is what I needed doing – you didn't do it - look at that now and see what's wrong with me."...'

One could say that this encounter was little different from many encounters between patient and doctor – a common tale of an overstretched NHS. My reason for including this passage is that the man felt his treatment was poor because of his ethnicity and the story is often repeated. So, whether it is true or not it will, if repeated only as gossip, begin to have currency within the close ethnic Pakistanis networks in the area after a time. After many retellings it may have achieved the status approaching 'fact'.

Anastasia continued to talk about the problems her father had encountered with Health Professionals:

> '...my dad really hates the health system over here. He does really get up-tight if he's like – he even goes to our local doctors. I mean Dr W's our doctor but I think he sometimes sees that lady who's Dr H. *And he comes back in a really foul mood* because *he* thinks he's treated differently.'

So we have another story about a man who sees that, rightly or wrongly, he is '...treated differently...' by a Health Professional. It does not really matter if he is right or wrong, the perception of being treated as 'other' is present. He believes there is a problem and therefore it is, for him, a reality with all that that entails.

These two stories mesh with the suggestion that Health Professionals have differing perceptions of Asian and non-Asian patients (cf. Ahmad 1994; 1996). Or at least the ethnic Pakistani patient feels it to be so. The perceptions that Health Professionals hold about

South Asians are said to be i) that they required longer consultations, ii) are less compliant than non-Asian patients, and iii) they make excessive or inappropriate demands on the health service. It has also been suggested that Asians qualified as doctors were less sympathetic to their Asian patients than their non-Asian colleagues. This attitude was also borne out by reports given to me regarding some South Asian GPs.

This may also be supported by the finding of Alexander (1999). In 1998/99 1,451 people in the UK were removed from practice lists at the doctor's request - usually citing the breakdown of the doctor/patient relationship. From the surnames of this group Alexander suggests it is possible to assign names to ethnic groups. She suggests that 531 (36.6%) '...appeared to be Indian, Pakistani or Bangladeshi...' - thus this group are almost four times more likely to be excluded from access to a GP than the rest of the population (Alexander 1999 31-32). If this is the case then the high levels of ill health felt by British Pakistanis discussed above[103] may begin to come into sharper focus. As Alexander states:

> 'It is still not clear to what extent institutional racism and culture and language barriers impact on service utilisation rates. Such information is important in planning appropriate services and supporting a broad-based community provision, including that offered by the independent sector'.
>
> (Alexander 1999, 32)

I would agree with Alexander regarding the problem of institutional racism but I, rather than seeing language as being another indicator, suggest that attempts to address language barriers are a causal factor in the perpetuation of institutional racism.

One of the key indicators of this perceived conflict between the two sides is non-compliance with Health Professional's advice. I suggest a possible explanation might be the cultural seclusion of members of this population. In my youth we were all rugged individuals (or so we believed) and chose to conform, or not, by personal choice. Over the period of audit culture's ascendancy we have become much more risk averse and thus much more compliant. I postulate that this compliance culture (audit enacted) has spread to all

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[103] Pakistanis reported to be ill or feeling unwell at twice the average of those in the ethnic majority.

walks of life. Ethnic Pakistanis have, for whatever reason, lived an insular existence, complying with the state only when absolutely necessary. Thus the 'revolutionary' nature of the UK population is 'alive and well' among ethnic Pakistanis – but today that revolutionary stance is frowned upon by the rest of compliant society.

Islam is often seen to be a further area of confusion and misunderstanding between the two sides. I see a simple solution here. Very early in my research I asked Rauf, one of my informants, how I could best find out about how Islam impacted on my research. Rauf produced a copy of the *Qur'an*, in English with a commentary, and said it would help me to understand. We began, over tea and biscuits, first to look up words, in the index, that might be used in my research – for example 'genetics'. We continued looking up references in the index of the *Qur'an*; then read the relevant *Surah* and commentaries. It took scant minutes to sort out issues that were central to my research. The relevant *Surah* told of how Islam perceives conception and foetal development, which is not at all dissimilar to modern genetics. These parts of the *Qur'an* also have a direct bearing on issues related to termination of pregnancy. I discussed these issues and the *Qur'an* later in the research with several Imams, all of who agreed with my analysis of the state of play in this regard. I still find it odd that lay Muslims and Health Professionals have not taken the few minutes to gather relevant information and add it to their knowledge when dealing with these sensitive issues.

Helman suggests that 'Cultural background may be a misleading explanation of the inequalities of health in a society' (Helman 1990b, 21). What is being said here? It is that along with culture there is often a multiplicity of shifting other factors at play (rich/poor, employed/unemployed, able/disabled, powerful/powerless) impacting on encounters and to ignore these is to fall into the trap of cultural reductionism. Ethnic Pakistanis and Health Professionals are complex people and the social criteria relevant to them are often in a state of flux – just like the rest of the human race. But the problem is that audit discourse locks onto the dimension of culture. Protocol is overlaid upon protocol – with the aim of solving

problems this has become the problem. Each problem gets a protocol, each new protocol is a problem, each new problem gets a new protocol, ad infinitum. These protocols fill ring binders, which in turn fill shelves. The problem persists. Both Health Professional and the gatekeepers within the minority ethnic communities are submissive to the state – this has to be so because the state controls funding, funding that is linked to performance criteria and target meeting and setting. A perpetual double helix of tension; I shall develop this later in the thesis.

I shall suggest there are no 'typical patients', culture is not static, thus assumptions about the 'other' tend to lead to mismatches between expectation and delivery. The potential for Health Professionals to make such errors of judgement on a daily basis, due to lack of knowledge, must be great.

CHAPTER FIVE

HEALTH PROFESSIONALS

In this chapter I want briefly to introduce the medical side that I worked with during this research and suggest how the enculturation process and work environment forms the basis of their perspectives. I look at their professional personas rather than their personal enculturations. The majority, in reality all but two, of the Health Professionals were white Northern Europeans, mostly women. The exception was the medical students who were perhaps one third men and two thirds women. The ethnic mix here was a little different as they were mainly ethnic South Asians (ethnic Pakistani bar one). This said, if you do not include skin pigmentation, all but one of the medical students also fall into a Northern European category, in the chief sense that they consider Britishness to be an important part of their identity.

I have spoken to the broadest spectrum of Health Professionals I could manage, including the proto-doctors studying medicine at the University of St Andrews, GPs in both England and Scotland, midwives and genetic counsellors in the two research areas, consultants in a variety of specialisms, and several other individuals who have crossed my path (mainly at conferences or during my personal interactions with the profession) during the past five years. Some have been, shall we say, less than sympathetic to my research, but the vast majority have been patient and supportive of my attempts to understand what they do and why they do it.

One of the most exciting groups of 'medics' that I talked with were the medical students. It came to me in a flash of inspiration whilst working as Door Staff (economic necessity) in the St Andrews Students Association – what better group to talk with than those who straddle the realms of lay and professional - the doctors of tomorrow? I will relate some of their narratives shortly – some of which surprised the tellers and gave them an insight into the unlooked-for effects of their brief period of medical training.

The GPs:

My first visit to Dr H, a Riverside doctor, took place in 1999. The meeting had been set up after a conversation, with Shaguffta (who I had tutored on a RSA Community Development course), at the *hakika* of another informant's son. Dr H was Shaguffta's brother-in-law. Shaguffta wanted her portfolios back from the RSA course and it was agreed that I would meet with her, at the doctor's home, to drop off the portfolios.

I checked at the college and the portfolios had gone missing, I was told that there was no sign of, nor hope, of finding the files. I telephoned Shaguffta and told her of this. She said that she had not had time to talk to her brother-in-law. It was quite clear that if I wished to access Dr H from this direction I would have to find the lost files. Perhaps this was the first instance of *lena-dena* - 'taking-giving' - that I had encountered with ethnic Pakistanis? After many adventures and some sleuthing I 'acquired' the portfolios.

I again contacted Shaguffta and told her the good news; she asked when she could collect the files. I offered to drop them off for her - when I met with her brother-in-law. I was learning the rules of the game. She agreed and set up the meeting a few days later. When I arrived at the doctor's house I was met by the doctor's wife and Shaguffta. I was told the doctor was out on call – 'Would I like to wait..?' I waited, but he did not arrive so it was suggested that we should meet on another occasion. I agreed to return the following evening - I was not about to lose access to my first Health Professional, not after all of the trouble I had gone to get this far.

This generated several meetings with Dr H, both at his home and in the surgery where he worked, in North Shore. He was very interested in the research I proposed and offered many insights into the world view of ethnic Pakistanis and specifically the role of FCM. He also made a significant financial contribution to my trip to Pakistan, as he felt that it would offer me a practical insight into the UK Pakistani milieu. He described what he knew about genetic screening and protocols with regard to thalassaemia and FCM in Riverside. Which was limited – he thought 'someone came down from Oldfort, if there was

a need'. He was vague on this matter as he had no occasion to investigate or test the protocols. One thing that he was all too clear about was the institutional racism and individual racism within the NHS. He recalled experiences of consultants who were openly racist not only to his ethnic Pakistani patients, but also to him personally. These included longer than usual waits for referrals and poor treatment[104] of those referred. With regard to institutional racism he said that the very fact that his patients were perceived as being different by the ('white') Health Professionals, which was seen clearly in their actions and demeanour, concerned him greatly.

I spoke to other GPs in both Scotland and North England over the period of the research some of whom had had personal experience of FCM and the potential genetic consequences of such traditional marriage practices. I sent out a brief questionnaire, by post, to all of the GP practices in the areas of study. I also talked with many of them about the New Genetics in a more general sense and relate their narratives in this part of the thesis. One of the clearest impressions I got from this group was that their knowledge, and often interests, were little different from lay members of the population. Their time was taken with day to day doctoring – genetics was very much 'other' to most of them.

Midwives:

My encounters with the midwives, in Riverside and Scotland, came in the latter half of my research as it was not until then that I realised how their role and my research interests intersected. I found them, along with genetic specialist midwives (GSM) and genetic counsellors, to be one of the most profitable seams of knowledge, experience and insight. Midwives deal with the day-to-day results of the screening of pregnant women and as such are seen as the front line in this project. They are involved in a dual role with responsibility for both the mother and the [unborn] child. The doctor is often only involved at the behest of the midwife, in many cases. The GSM is perhaps more knowledgeable then the consultant obstetrician or gynaecologist that they work for, in matters of genetics. It is also within this group that the effects of audit culture are most clearly discernible. Their

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[104] Here I mean interpersonal rather than clinical treatment – often referred to as *bedside manner*..

stories tell of what was and what is in this realm. They are also perhaps the most willing to consider new perspectives and try to modify their behaviour (although only within the bounds allowed by systems of protocols and guidelines which delimit their role). They were often found to be walking a tightrope between what is required for best practice within health authority guidelines, and what is best for patient care.

One of the reasons for my return to Riverside, in 2003, was to speak with some midwives, now that their role within the National Screening Programme for the Haemoglobinopathies (NSPFTH) was more clearly defined. In Riverside the situation was somewhat different from that in Scotland. I spoke to Freda, a midwife in North Shore, about her experiences with the haemoglobinopathies and ethnic Pakistani women. She was covering both GP surgeries, in Riverside, when I first met her, so she was able to give an insight into the practical situation in both practices. Freda had not been working at the surgeries for long as she had only recently taken up the post. Freda told me that some procedures were undertaken 'on own initiative' based upon protocols followed in other health areas that she had worked in previously – more experience-based than evidence-based, one might say. As noted above, knowledge of protocols related to thalassaemia, in North Shore, were from a GP whose knowledge was limited. Returning to North Shore nearly five years later I found little had changed, the protocols remained something of an unknown quantity.

Genetic Specialist Midwives (GSM):

At the beginning of my fieldwork in Scotland I had heard that there were genetic specialist midwives (GSM) – but how to tell them from their more numerous counterparts? I followed what had become my standard operating procedure in Scotland. I walked into the Maternity Unit at Poundtown Royal Infirmary (I was there undergoing minor surgery) and asked whether there were any GSMs working at the hospital? The midwife I spoke to did not know, but she gave me the name and telephone number of the Genetic Counsellor (GC) who worked in Citadel. I met with the GC at City General a few days later. From this

meeting I was given the names of the GSMs who worked at Poundtown and Jamestown hospitals. I made my approach to them, saying that Jade, the genetic counsellor, had given me their names. All seemed to go well. However, I found that, Martha, the GSM at Poundtown was not too keen on my observing her work. I was told that I would have to talk to her line manager – which eventually took about eighteen months and resulted in my being told that I needed Ethics Board Approval (cf. Strathern 2000). Her counterpart, Jane, at Jamestown could not have been more different. She was keen to help with my research and also interested in hearing what I had learned and putting it into practice where appropriate.

I met with another GSM in Coldville Royal Infirmary and one in Cakestone Infirmary. Francis, who I met at Coldville Royal Infirmary, was very keen to get involved in my research and we made plans for future joint projects. She said that she would have to get approval from her line-manager, the clinical geneticist in Bondville. Francis thought that this was merely a formality as what I wanted to do and the educational remit of the GSM fit hand-in-glove. Unfortunately this was not the case. I received a rather terse e-mail from the clinical geneticist in Bondville in reply to my letter – the main thrust was that there was no interest in ethnic groups, as there were not enough to concern her. In Integerpool Hospital it was the opposite, the Clinical Geneticist was happy to work with me, but the GSM was not.

The hierarchy within the different Health Regions (i.e. Riverside and Central Scotland) was very much the same. That was: the first point of contact for the pregnant woman would be the GP and community midwives, on from there to the antenatal clinic and GSM if there was one, failing that from the midwife onto the specialist in the relevant department – be that obstetrics, gynaecology, clinical genetics or haematology. If there were indications of a high potential risk of genetic malformation the GSM was the first line of contact. If there were no GSMs or genetic counsellors then the role was filled by a combination of obstetrician and haematologist. Although occasionally, I was told, there may be problems of demarcation, and territorialism was still seen as a major stumbling block for

effective patient centred treatment in these instances. This, it turns out, was the underlying reason behind the lack of interest from the clinical geneticist in Bondville.

The difference between Martha and Jane, both GSMs, was marked and leads me to argue that it is the individual's actions and interest that makes for better patient care, not any amount of best practice, that is, conforming to the lowest common denominator. Both Jane and Martha were trained by Jade and both were part of the same hospital group. Both shared the same line manager, both worked with the same consultants. The only difference that I could perceive was in their personal motivation.

Jane agreed that perhaps people were scared to talk or have their work observed. In the professionalised world it is problematic to be scrutinised without first knowing which 'ticky-boxes' or performance criteria were being measured. Furthermore, she thought that the culture of the ethnic Pakistani side is in some senses alien to the white Health Professional, although every effort is made to develop knowledge and take this into account when interacting with patients. As she has seen only a few South Asians in her role as GSM and those about two years ago, she said she has had little call to investigate further.

I ask if her job has changed since she first became a midwife.

'Yes, there's a lot more paperwork now. There are guidelines for everything and procedure to cover virtually every aspect of the job.'

She told me that her role was mainly talking to people and explaining genetics to them rather than delivering babies. But she keeps in contact with other midwives, and they had told her everything has changed within their milieu, and not all for the better.

Genetic Counsellors (GCs):

I met only two GCs during my research, one at a conference who 'turned me on' to the thalassaemia/FCM debate and one in Scotland. All of the other areas did not have trained genetic counsellors, Jade, a GC I spoke to in Scotland, had come via the nursing pathway and had experience of working with the haemoglobinopathies in North Africa and so had developed a keen interest from that time. She also had a degree in Human Genetics

and was trained in genetic counselling. One of the key battles she told me she had had was in gently letting the experts in the diseases know that they *are,* and will remain, the experts. It had taken some years, she told me, to navigate the territorialism within the health service, but she is now seeing results for her efforts.

It was clear from our conversations that she was motivated and committed to a process of education, which was essentially a long range stratagem. Jade told me that it may be five years after an initial contact with a family that any tangible results are seen. Often people will also talk to her about genetic issues, say before starting a family, if there is a known risk within close family. This is part of the 'best case scenario' where individuals are counselled pre-conception and have time to make any decisions without a time-pressure being added. There were also plans for the future, specifically the placement of people with genetic knowledge to be developed in GP practices and other primary care venues. This would further add levels of access for individuals to obtain genetic knowledge pre-conception. This commitment to patient centred care is typical of those motivated individuals, working within the constraints of audit, that I met during my research.

Specialists:

The difference between the work of a GC or GSM and that of the Clinical Geneticist is with levels of genetic complexity. Clinical geneticists are expert in the more complex areas of genetics for example dysmorphology, pattern recognition and the more difficult diseases. The role of the GC ends where the expertise of the clinical geneticist begins. There is an exchange of information and the knowledge between the two practitioners, so each makes an appropriate contribution to the service. It is rare for a clinical geneticist to be directly involved with single gene disorders.

The specialists I spoke to, or attempted to speak to, were mainly clinical geneticists and haematologists. Although this group had information to relay I did not take much time to pursue them. Rather I talked to them on specifics and took clarification on some matters as their day-to-day involvement with the areas that interested me was limited. Some were

too busy to talk to me or rather not interested in either my research, or the ethnic Pakistanis that I was working with. The exception was the Integerpool Hospital where I was able to discuss my work with both a Clinical Geneticist and a Professor of Haematology. In addition, the geneticists in the North of England were literally just setting up their operation in Ironopolis, as I finished my fieldwork[105].

Although I had problems accessing some Health Professionals as I was an 'outsider', a non-clinician and worse a *student* I was still able to gain valuable insight into their work and also check my lay knowledge and findings against their knowledge and experience. This system of checks and balances used at the end of my fieldwork has allowed me to confidently make statements in my analysis that might otherwise not have withstood scrutiny. As they have the support of the experts in the field, I have been able to expound them here.

Enculturation by education and work within the NHS:

The process of enculturation within the National Health Service is fairly clear and uniform. To qualify, individuals engage in education and training processes in which they undergo a standardised change. In addition, after qualification, they are enculturated into the processes and procedures of the workplace. These may vary slightly from region to region depending on priorities highlighted and personnel employed. A further, and I argue more pernicious, process is enculturated via the increasing number of protocols, introduced piecemeal, over time. Each time there is a problem highlighted, that is a criticism of the NHS or some litigation, a new protocol is set in place to ensure that the problem does not arise again. Additional protocols are introduced to meet the needs of inspection and adherence to targets set by politicians. These changes are, as discussed previously, small and apparently innocuous, but build up over time and engender change to such an extent that often what went before is no longer recognisable – a *simulacra* if you will.

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[105] I e-mailed Oldfort and asked if there was anyone in Riverside who dealt with the areas that I was researching. I was told there was going to be a centre set up in Riverside in the near future. My e-mail (and questions) was forwarded to the consultant who was to take up the post in the very near future. I received replies from both Oldfort and Riverside, which was helpful. However, I was unable to wait for the setting up of the facility due to the need to draw the fieldwork to a close.

Muslim medics:

I met several Muslim medics. Some were medical students and one was a doctor at Integerpool Hospital. The key issue that caught my attention was their take on evolution, or more specifically evolutionary biology and its relevance to current genetic thinking.

Evolutionary biology texts (Aiello et al: 1990[106]) are available for the use of the 'medics' (first, second and third year medical students) in the University of St Andrews library. So, I would argue, it is a reasonable assumption that similar texts are also available in libraries used by all trainee doctors (medical students), who are, upon completion of their studies, licensed to practice within the NHS. This being the case the Muslim doctor I spoke to at the Cakestone mosque must have had access to such knowledge. Yet he was quite happy to ignore such a large body of medical/scientific evidence, because it contradicted his understanding of Islam. The Muslim students (medics) that I spoke to as part of my research were equally happy to disregard any teaching that was contra to their Islamic world view. Much of the knowledge used to heal comes from the work of evolutionary biologists, anthropologists and psychologists. All is ignored because it is problematic for their creation myth, which is in essence the same as that believed by Christians (see Genesis 1,1; Surah 7, 54), if they accept evolution as fact.

If both medics and practising Muslim doctors hold this common shared belief system then this must, in turn, affect how they inform patients regarding genetic issues. Again this becomes problematic in several ways. For example, patient's informed consent is put at-risk. The risks of continuation with the pregnancy and also those risks which come postpartum may be skewed. This skewing may also be significantly enlarged due to the power relationship between doctor and patient. These factors are again considerably heightened as many Muslim men and women may actively seek out a Muslim physician. Perhaps I am being naïve or have too high an expectation of medical practitioners or have not grasped the argument I have already put forward that medicine is an enterprise, not a

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[106] Aiello, L & Dean, C (1990) *An Introduction to Human Evolutionary Anatomy* (London: Academic Press)

science. The out and out denial of something that is evidenced by their daily work, as medics, troubled me.

When I asked the student medics how they reconciled their beliefs, which in all cases was fundamentalist[107], with what was taught within the classrooms of St Andrews they all said that they wrote the answers that would get them through the module, but took no notice of the bits that did not fit with their previous beliefs. This closed-mind attitude exhibited by the new generation of doctors was quite frightening. The audit culture world that is the modern NHS, where there are standards, protocols and standardised approaches, all of which are thought to give a minimum standard of health care across the NHS, is potentially voided by those who are locked into a mindset that finds it acceptable to ignore science and operate on blind faith. I am well aware of the term 'GOK[108]' used by doctors on patients' notes. The need to 'change the hearts and minds of a generation' to remove institutional racism from the NHS may not be the only barrier to better, more effective and thus cost effective health-care within the NHS. All of the work put in by the GC and GSM will come to nought if science is deliberately ignored in favour of religion. The opportunities offered by the Human Genome Project and national genetic screening programmes which offer the chance for patients to have information to make informed decisions with regard to risk will be negated if practitioners choose to ignore any data that does not fit their mindset. This mindset is not universal among Muslim Health Professionals, as evidenced by Khalid, Dr H and Shaguffta. However, my research suggests that these people may well be in the minority.

The doctor and the men at the mosque in Cakestone vehemently denied the validity of the evolutionary nature of life on Earth despite all of the overwhelming evidence of the previous century and a half. The juxtaposition of religion and science for these men was not incongruous – their argument was that the *Qur'an* was based on science, and thus proven fact – yet they held to a set of beliefs that denied logic or the gift of freewill granted by

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[107] I use the term in its true sense of one who holds to a literal translation of a religious text, in this case the *Qur'an.*
[108] GOK = God Only Knows

Allah (HNBP[109]). The doctor based his position on the power and status afforded him by his medical degree, yet offered interpretations based on faith and not based on post-enlightenment science. This disengagement of the intellect when medical-science appeared to come into conflict with Islam was also seen in the discussions that I had held with the Muslim medical students. To further confuse the picture, a man like Abdullah, who owned and worked in a Tandoori take-away in post-industrial Riverside, was able to come to grips with complex bio-ethical issues much more readily than the more 'educated' medics – at whatever their level of progress through the system.

I asked one third year medical student how Islam and what she had been taught about genetics and evolution fitted together. Amun responded: '…there was something that was contradicting, yes, a great chunk of genetic stuff was contradicting what's in our religion. But then we [Muslim medical students] have to read it and get distinctions in it, basically learn it even though we don't believe in it…' Amun continued by explaining how evolutionary biology was problematic for her and her friends: '…the fact that we've been evolved from monkeys…to be honest, [we are] far more superior than the monkeys so there is no way we can develop from monkeys… fair enough monkeys are *similar*…, there's similarity between them and human beings but… there couldn't be a link between them…. they try to say our hands are the same…' I tried to engage in some discourse regarding current knowledge of evolution and the evidence to support such a thesis. But, as with all of the Muslim Health Professionals I have spoken to on this subject, Amun shut out any thought on evolution – it was wrong and therefore not worth considering long enough to make an educated decision.

If this is the position of the educated and also trained Muslim Health Professionals, then how can one expect to introduce concepts of genetic risk to lay Muslims? There is a mind-set which precludes informed consent as Muslims do not believe the evidence presented by the New Genetics. If they do not believe in the basic premises of genetics, but do believe in the *Qur'an* as the true word of god, then informed consent cannot be achieved

[109] His Name Be Praised.

when discussing perceptions of genetic risk. Mutation, whatever that might be, and congenital defects are the 'Will of Allah.' And I would be hard pressed to suggest a way around this fatalistic perception of risk, and thus move towards risk aversion.

The Medical Students:

The students were in their first, second or third years of their medical training and as such had not seen a 'live' patient. However, what they could tell me about their training and their experienced realm was very useful in constructing a picture of the enculturation processes at work. The social class of these informants was mixed – but one would have to say that the majority were from the higher levels of the Registrar General's classification[110]. As I have said they were all born in Northern Europe with the exception of one who came from Northern Africa. Many of those I spoke to came from medical families and as such were able to offer insights broader than their own lived experiences.

Having explored the Health Professional side I now turn to the ethnic Pakistani side and consider how risk is enculturated within their overlapping realms.

[110] See Goldthorpe 1987.

CHAPTER SIX

ETHNIC PAKISTANIS IN THE UK

Ethnic Pakistani identity in Britain:

British Pakistanis are not a subculture as they are diverse and heterogeneous in their daily lives and part of the broad culture that is the UK. However, for the purpose of this thesis I intend to examine their interactions with Health Professionals as a subset of their ordinary daily lives. I suggest that this interaction marks them off from the broader society.

The Asian Survey (1982b) carried out by CCRI[111] stated that 74% of ethnic Pakistani adults, in the Riverside area, were born in Pakistan and 10% in the UK (ibid, 4). Of the Pakistani children mentioned in the survey 42% were born in Pakistan and 49% in the UK (ibid). This suggests that most of the ethnic Pakistani population in Riverside was born in Pakistan and thus one could expect concomitant problems with the English language. However, I know of many children recorded as being 'born in Pakistan' whose mothers travelled to Pakistan whilst pregnant to be pampered by their own mother; after the birth they travelled back to the UK. These children attended the UK education system. For this reason, I suggest they possess strong English language skills. One example of this is Sabia, Lutherfur's daughter, who was one of my students[112] whist I was a lecturer at a college. I am aware of many other families where this was also the case. This may give some explanation of the small numbers of 'Pakistani' births encountered by midwives in Riverside and Scotland. In both areas studied the South Asian population is growing. As the draconian immigration laws prevent large numbers of people from migrating to the UK from Pakistan one must assume that the increase is due to births - whether or not these births are observed by the midwifery profession. CCRI's earlier 'Inner City Health

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[111] Cleveland County Research and Intelligence Unit.
[112] When I last visited Lutherfur, in mid-2003, Sabia was a student away at university in Manchester.

Education Survey'[113] (1979) indicates that the South Asian population in the UK is very young, compared to the general population. We then must accept that these people have more than likely passed through the UK education system, and I argue, we can reasonably assume that communication in English is not going to be an issue for these individuals.

I asked many of my Riverside informants, why the assimilation process so evident in the late 1970s had taken a dramatic u-turn. The main reasons fell into expected categories - an increase in xenophobia/Islamophobia and growing unemployment in the nineteen-eighties and nineties had made the ethnic Pakistanis more inward looking and more 'traditional'. Many particularly mentioned the return to a fundamentalist interpretation of the *Qur'an*. I asked Sajid about the apparent increasing return to basic Islamic values and beliefs over the past twenty years. He said that high unemployment (cf. Lawless 1995) and increase in racism has brought men back to the 'fold'. Another factor was that many of the older men were now becoming prone to disease associated with advancing age and also life-style related conditions, and were nearing death. Sajid had undergone a heart bypass operation in early 2003 and many of his friends have either had such operations or had heart disease. As for the younger generation a new radical Islam offers hope for their future – even if it is the 'jam tomorrow' promise of Paradise for being a good Muslim – a comfort in an ever more unsettled world. Had this not been the case it may well have led to a continuation of the trend towards a more integrated British population.

For many, the UK is their country of birth – they are British in every sense of the word. Yet they are perceived as alien by many and with the increase of Islamophobia post 'September 11th' they are increasingly driven to the 'safety' of the mosque and a more inward looking and introspective Islam. This increased reliance on a narrow and culturally biased version of Islam must have an impact on how people perceive and interpret

[113] Undertaken by CCRI for the Riverside Area Health Authority. This tells us – '...51.2% being under the age of sixteen...' in 1982. Again this militates against the suggestion that the English language is problematic for South Asians in regard to accessing health – and birth related issues in particular.

information from 'outside'[114] - with regard to the topic of this research, genetics and potential risk from congenital birth defects.

The very interpretation of risk is coloured by this introspective world view. For example on my last visit, after Sajid had undergone a triple-bypass for his heart, he told me that he had been told to cut down on his fat intake. I asked how it was going. (I knew there was a 'Cooking without Ghee' health initiative in Riverside some years ago to address just this issue.) He said he had not changed his diet: 'Allah will protect.' This attitude, not uncommon in Muslims, may well militate against any medical advice being heeded by ethnic Pakistanis. If something that can be seen (Sajid was very keen to show me the scars from his bypass operation) and understood like heart disease goes unconsidered how much more difficult might it be to discuss the imagined risks attached to genetic disease – it cannot be seen or felt. If one adds to this the attitudes described elsewhere in this thesis, particularly those held by Muslim medics, dialogue is going to be increasingly problematic.

Ethnic Pakistanis in the UK are often subversive. It is not difficult to see why false perceptions, particularly in regard to language, of this side are often held by the state. An example of this misdirection can be seen in the following story. I was asking for clarification of aspects of a partial family tree I had began to construct after the previous day's conversation. I asked for the names of the person's family, starting with his full name. Mr Uddin switched from the 'semi-educated Pakistani' with little English, to an urbane businessman who spoke perfect and unaccented English to say that his full name was – and he spelt it for me - Choudhry. He then told me that was the name on his passport also, and that was also how the banks knew him. He explained, Choudhry was his family name, not his given name, and he uses it because it is easier than explaining the complications to everyone he does business with[115]. He focused intently on the genealogy and pointed to his

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[114] An example of this can be seen in the reaction of Muslims and non-Muslims to the episode of the BBC TV programme 'Spooks' which dealt with a Imam in a mosque (in a fictitious part of Birmingham) training 'suicide bombers'. After the programme was shown vandals '...daubed offensive graffiti...' on the walls of the Central Birmingham Mosque. (http://www.nation.com.pk/report/uk-com/page7.htm)

[115] Choudhry, he told me, translated into Headman, in his village in Pakistan. Thus Choudhry simply meant that his family supplied the Headmen in his village, it was a 'job-title' not a given name. But rather than explain this to the immigration officials he just allowed the state to make the assumption. A similar story was

wife and began to spell her name for me. Then appeared to misunderstand something I had said; suddenly I hit something of a 'brick wall' as I tried to complete his family tree. I asked about his oldest daughter's name. He said he could not spell it and I should just write 'G. Uddin'. The strong accent had returned and he re-entered the role of 'uneducated Pakistani'. So a man from the first generation of migrants, the group that the state identifies as most likely to need translation, speaks perfect, unaccented English.

Ethnic Pakistanis exhibit an apparently strong sense of duty and adherence to rules, yet they also display a total disregard for authority on other occasions. An example that I observed was behaviour in an aircraft after landing. My plane landed in Karachi and as soon as the reverse thrust of the engines was applied everyone was up out of their seats – a mad scramble to get their belongings out of the lockers and head for the doors. The stewards were telling everyone to remain seated until the plane stopped. No one took any notice of what the stewards said or did. The landing at London Heathrow was somewhat different. The stewardess shouted at the passengers to remain seated – those who had begun to get their hand luggage from the overhead lockers sat back down. This was in marked contrast to the events of both landings in Pakistan. This disregard for 'polite' authority may also explain attitudes to Health Professionals and also have implications for non-compliance. A similar conclusion can be reached with regard to a doctor/patient interaction on a thalassaemia video I was shown by a genetic counsellor in Scotland. The doctor 'threatened' one young man that if he failed to comply with treatment he would die very soon. The problem with audit culture is that it relies on the patient receiving all information, then making a decision on that data – take it or leave it. Free choice, free will – but this attitude will often not lead to the best outcome for the patient as it is non-directive and cultural norms would suggest it will lead to a non-compliant outcome.

However, I was told by one young Muslim woman, Tasmin:

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told by a man whose was 'renamed' by an immigration official who misread his name - his father's handwriting was poor. He has allowed this 'error' to continue unchallenged - 'it's much easier than arguing with them'.

'...my family all trust doctors and everything so whatever they did I think they would just agree with it because people from Pakistan they all know that the health care here is much better [in the UK compared with Pakistan] so anything you get here is worth taking and they all trust the doctors. I know my mam does, she just takes things.'

Her friend Rahana added:

'I think my family is a bit different, my mum is a dentist. So she knows herself more or less what's going on... But I think I agree with Rahana that in general the Pakistani community is insular and tends to do whatever the doctor says.'

Rahana agreed with Tasmin here, further adding: 'Doctor's are a very big thing.'

Tasmin continued: 'In the community doctors are like a big [pauses] *idols.'*

Both women laughed and suggested that 'idol' was perhaps not too strong an image in this instance. This suggests that there is a very fine balance between ensuring patient compliance and a very strong sense of unequal power relationship between the two sides.

I asked another informant if he intended to return to Pakistan at some point as the UK was becoming even more racist and he had voiced concerns that his children were losing their Pakistani heritage. He replied: '...there is no one left there, all family are now living in the UK or dead'. He continued: '...I only have one close relative left in Pakistan. There is nothing to return to'. This picture is repeated many times among the people I have talked with in both England and Scotland. All of their children see the UK as their home and see themselves as 'British'. Which will lead to confusion for the children as the British state continues to perceive them as 'aliens' who need separate and unusual treatment. I then asked the informant about marrying someone from Pakistan when it came to his children's marriage – perhaps from the *biradari* or wider family? He said that he thought that they would probably marry someone from the UK, they would have no links to Pakistan, his parents lived in the UK, and his wife Shakira's parents might be dead by the time they grew up and wanted to get married.

It is not just the younger generation that perceive themselves as British. One old man told me of a recent trip to Pakistan to see his brother. He related a story of how his brother had asked him to bring him back 200 Benson & Hedges cigarettes and a small bottle of whisky [for medicine]. At the customs desk in Pakistan he was told he was not allowed to have the whisky, but could keep it if the customs officer could have the 200 B&H... He refused saying: '...I am British, I can take it anywhere...' He perceived himself to be British when it came to his 'rights'. He also saw the UK as his home in other ways also, for example, he saw his trip to Pakistan as a holiday and not as 'returning home'.

This sense of Britishness was also felt by Sabia, a Muslim woman I met in Riverside, Sabia, was quite clear that the negative view of Muslim women, often portrayed in the media, is inaccurate and was often at pains to offer me evidence to dispel the myth. I suggest that this media perception of Muslims, for example oppressing their women folk, is not too far from that held by many Health Professionals. Certainly many other ethnic Pakistanis have also voiced their concern with regard to this stereotyping of their people. Her friend Julie added: '... there is a difference between culture and Islam... a lot of Muslims in Riverside; they've like adopted a culture that isn't Islamic. I mean... culture is just the values and beliefs that come down from generation to generation but those values and beliefs often conflict with Islamic beliefs... for example... forced marriage, that's cultural... people who are Muslim like adopt cultures ... like they prefer the marriage when they're doing rituals.. they've adopted them from their [Hindu] culture... people who are more Islamic like don't take part in such rituals. Also engagement rituals are also adopted... we [Muslims] aren't supposed to do that sort of thing...'

Another informant, whose father was born in Pakistan and whose mother was 'white' English had a very clear view of 'Asians' and more importantly how she positioned herself. I outlined what I had read in the literature (Ahmad 1991 1994 1996; Proctor & Smith 1992) about Health Professionals' negative perceptions of Pakistanis in Britain. Anastasia commented:

'Oh yeah, that is true [Laughs]. Especially the being late all the time [Laughs again]. I'm trying to think of examples but [pause] there are a lot of Asian people, not within the village where I live, but in town – I mean *they* have special *areas* don't *they*... I always think they smell of BO as well [laughs]. I've just got this general view – like they're quite arrogant as well. You can be walking down the street and they just push past you. And I always think they smell of BO, I don't think they use any deodorant at all [Laughs]. I'm talking about them myself here, I should be considering myself as that [Pakistani] as well. But I've got these *stereotypes* of them [Pakistanis] myself...'

This young woman would be perceived as 'Pakistani' by Health Professionals and dealt with according to protocol. Yet it is quite clear that she saw herself as British and clearly separate from 'Asians'. This is becoming increasingly the case in the UK[116], and yet the NHS has not addressed this issue. I mentioned earlier that this sense of felt identity and ascribed identity would cause conflict for Razwan's children when they grew up. Anastasia described this conflict in relation to the Equal Opportunities pro forma she was required to complete for the university, as a student. She said that she had ticked 'other' for ethnic origin, not to be evasive, but rather because there was not a box that she felt described her – she was British, born and bred.

Education is a key factor in this change. Sabeeya, like many Asians, saw education as central to '...getting on...' Also the British education system is delivered in English, the playground language is English, and the children's friends are English (no matter how much *melanin* pigmented their skins). When they return home they talk English as their first language. I talk more specifically of this later. But here I would just suggest that the education system, and to an extent the workplace, has informed a more westernised enculturation for ethnic Pakistanis in Britain.

I suggest that these rapid changes in perception of self are important and are summed up by a woman born in Pakistan who moved to the UK ten years ago and now has five

[116] According to my informants.

children, three of whom are in school. When we first met, her English was poor, but at our last meeting in 2003, she was fluent. Also the conversations with her children were all in English. She told me the first day we met that: '…we just wanted to be treated the same as everyone else in the UK'. Her husband agreed with her.

Islam and genetics:

Religion was not a significant factor for South Asians during diaspora (Knott 1997; Lawless 1995) but has now become more important in defining their ethnic identities. This is evidenced in dress, festivals, religious buildings and artefacts (Knott 1997, 756). South Asians in the late twentieth and early twenty-first centuries have often been referred to, for example by the media, the state and thus society in general, as Muslims, Hindus or Sikhs rather than Indians, Pakistanis, South Asians or, perhaps more accurately, in many cases, British. However, as time has passed Islam, and more particularly the mosque, has increasingly become a central feature of daily life. They have both, in some senses; become a refuge and a shield for ethnic Pakistanis here in Britain. One factor in this movement is the rise of Islamophobia and the impending Christian Capitalist *'jihad'* which are gathering momentum as I write.

Knott further suggests that places of worship have become central as places to congregate and act as social and cultural centres in addition to their religious function (Knott 1997, 756). Furthermore, these religious centres are pivotal in accessing local government grants and furnishing delegates to represent the community in committees within the wider political landscape. Also, they act as focal points for health initiatives, education and as points of access to people from outwith their 'community' – for example researchers. This centrality is further referred to later in the thesis.

I often asked how ethnic Pakistanis thought Health Professionals understood and perceived Muslims. The main issue that I wanted to address was whether they thought there was any difference between the ways they were treated within the NHS. More than one informant was quick to point out that the difference between:

'…you and us… we Muslims always worry about the order of God…'

One Imam, in Cakestone, said the difference between:

'…the people from the west and the people of the east…is that the people of the east asked: '…"What does our God order?" – what is the command of Allah on this point…'

He then said that all other questions flowed from that. Sin was paramount; all other decisions were secondary to Allah.

I was talking to two young Muslim women about why they thought there was a growth in interest in Islam. The first told me:

'…[it] is probably to do with more people having knowledge and there's a lot more provision these days… most of the [Islamic] scholars are really educated and use videos in English so that people could understand it [Islam] …I think there is just more knowledge…'

It is also interesting that she felt it important that the education videos should be in English – further proof that English, not the South Asian languages, are the most effective means of communication with the younger generation.

The second young woman said:

'... the new generation…[that] have just…totally resisted everything [the old traditions from Pakistan] They are actually talking about Islam. They are not resisting their parents because of all this culture, that's crap… there's more debate about interpreting the *Qur'an* than rebellion… and educating their parents…' [laughs]

What she was saying is that young ethnic Pakistanis are rebelling not over tradition, although there is some resistance to that, but over the interpretation of the *Qur'an*. Many individuals, from the older generation, that I have spoken to have conflated tradition and Islam – the choice of FCM is often said to be religion, but if pressed they relent and say it is more custom brought from Pakistan.

There was also further evidence of how these two women perceived themselves during the same conversation. The first woman said that those members of the older generation, who were critical of the young, were often what she called:

> 'Muslims by name, not Muslims by claim. Just 'cos they eat curry doesn't make it all right to be a Muslim…'

She made several assumptions here; i] only Pakistanis are Muslim, ii] traditional South Asian food is an indication of a link between ethnicity and religion. More interestingly she positions herself as a good, and by assumption educated, Muslim. Many of the older (male) generation are perceived as *bad* Muslims because of the sins committed before the women joined them – that is drinking alcohol and womanising. Elsewhere both women talk about the adulterous relations some of the older men have with white women. These same men claim the moral high ground when talking to the younger generation, very often using Islam to make or enforce their point or judgement. However, many of the younger generation have studied the *Qur'an* and are able to rebut their arguments. Also, I think it is quite clear that both women see themselves as British Muslims, not Pakistanis. An indicator of this British element is by one of the women using of the word 'scarf' rather than *hijaab* in her everyday conversations.

I had asked the Imam in each of the area in which I worked for their view on my research and how Islam impacted on it. There was always discussion, but it was made very clear that what I was doing was OK with regard to Islam and was also research that was very much needed at this time. I would be told that the *Qur'an* described everything that modern western medicine and genetics was finding out. Several *hafiz* had told me that Allah created everything in the world – including the geneticists. It was also said that the *Qur'an* tells us that we should all learn as much as possible – education was a great good and counted towards paradise. I was frequently told that Muslims had a duty to raise healthy children. If something could be done to prevent a child from 'becoming sickly' then it should be done. Allah had created everything and for that reason how could genetics be

wrong? We talked about outcomes from my research and one *hafiz* suggested that a video, not a booklet, was probably the best method of passing on information to members of his 'community'. This he said was best because '…people are lazy…' He said that I had his full support in my research. We continued to discuss genetics – he felt, and I agreed, it was far from a perfect science.

Concerning Abortion:

I asked one of the *hafiz* I talked with about abortion and his answer was:

> '…if the child is already formed and the soul is already there you are not allowed to perform an abortion, before that yes…'

The Iman then offered further clarification. There were exceptional cases, where there was for example

> '…danger to the mother, very dangerous to the mother. It is better to, to, to save the tree rather than the branches. In certain cases, you know what I mean?...'

He continued

> 'It is better to save the tree than the branches. Like the branch goes away, but the tree is still there. There is another chance [the mother can become pregnant again in the future]…'

He amplified his point by saying:

> 'So the child goes away, in certain cases… but if the soul come, the breathing come than that is a difficulty… it is not allowed…Because already God has decided to do that, and soul is there already and breathing…'

So there is no clear, hard and fast rule in Islam. This is one of the reasons the GC at City General said that it is often better if the couple can say that the doctor (a powerful figure in this culture) said there should be a termination. In this way the couple deflect any pressure or censure from family and friends and are able to make a free and informed choice whether to continue the pregnancy or not.

The issue of whether Pakistanis will agree to abortion of a foetus if there is a genetic contraindication is particularly germane to the debate. There is no reason to suppose that Pakistani parents make such an intensely personal decision in any way differently than parents of any other ethnic group (Atkin 1998, 1644). As previously discussed there is no conflict with Islam with regard to abortion in the context that the soul is not seen to have entered the body until the one hundred and twentieth day post-conception (Modell & Petrou 1994 119; Ali 1996 *Surah* 46, 15 & note 4790). Unfortunately, the health service has tended to offer diagnostic genetic tests in the second trimester (less than 50% of first referrals are in the first trimester) (Modell et al 1997, 779) – which makes abortion problematic for this group. Thus British Pakistanis seem to suffer from a serious shortfall in antenatal screening policies and are therefore at-risk.[117] This lends some weight to Ahmad's (1994) argument that the high rate of congenital defects may have contributory factors other than FCM.

Quite frequently in discussion with Muslims, other than Imam, there are conflicting views of the abortion debate. Very often the people were quite widely read and claim to have studied the *Qur'an*, but there is little ability to engage in debate about its application. There is often a tendency to take a fallback position when confronted with knowledge that conflicts with their cultural norms and values. This position is to '…consult with the Imam…' This was often the case even if I was able to show them the relevant *Surah*. The next position was usually in the form of a question: 'Did you read this in a translation?' When I confirmed their suspicions there was a sigh of relief and I would be informed that only in Arabic could the true meaning be known – that is why I am mistaken. This position, I have found, is not unique to me - I have been told by several Imam that they get the same reaction from many Pakistani men.

I asked several groups of men how they would feel about their wife or daughter having an abortion, as long as it was on the advice of the doctor and before the 120th day. The consensus seemed to be that it was acceptable, in principle. However, they would not be sure about what they would do if it was their family. There was a strong sense that they

[117] However and by whoever 'risk' is defined.

would endure the 'test' set by Allah and would probably have the baby and look after it, even if it was sickly. The men suggested that they would talk it over with the Imam, though their wives were never mentioned in this process. After taking the Imam's words into account they would make the decision. So the women, who would undertake the actual care which would gain paradise for their spouses, would not be consulted. I made attempts to make direct links between these men and their women folk, mostly without success. The general feeling that I got from these encounters was that the men were quite happy to give me their opinions but did not want me to hear the women's views, as they might be at variance to those held by the men. Alternatively, they did not want their women to have access to the Islamic arguments that I had discussed with the men.

I spoke to one young man, who was an official of an Islamic Society at a university, and asked him about genetic testing for thalassaemia. He replied:

> 'Not really, no. I try to keep it the way it is. From a personal point of view but I mean in Islam it's permitted, you know. But personally…it would not make a difference. I'd want to have the child anyway.'

I then asked, taking into account this information, whether he was against abortion on principle. He said:

> 'Yeah, but it depends on circumstance. So, for example, Islam allows abortion if the mother's life is in danger. Then it permits it.'

So I asked him if that would be the only reason. Nasir said, 'yes, that would be the only reason'.

The vast majority of the men I spoke with said that Islam was very important, even above family, and they trusted Allah in all things. They thought, along with many others, that Allah '…never gave a burden that could not be carried…' Things were sent to test faith, but Allah's will was paramount. They mostly agreed that Allah had created all things, doctors and scientists included, and so it was good to know the new discoveries, genetics

included. Many also said that they would take precautions with their health and that of their families, but in the end it was Allah's will and what would be would be - *qismat*.

Doublerootedness:

Many of the cultural values of the older Pakistanis hail from the sending society. Werbner's (1990) 'doublerootedness' notion is borne out by the attitudes and values held by many of my informants. Often I have found that culture has a strong impact on perceptions of what is understood by people. But there are many factors intermeshing and interplaying within this. To take the example of the apparently simple cousin marriages between ethnic Pakistanis in the UK, more and more of my informants told me that they or their family showed a preference for arranging marriage partners from within the UK, rather than choosing from family remaining in Pakistan. Moreover, in the early twenty-first century there seems to be a change to this trend. Many fathers said that the only real limit was that their children marry Muslims. So this element of doublerootedness seems to be withering. This change may well be helped by the paucity of relatives remaining in the sending locality from which to choose, as I describe above.

A factor in the continuation of doublerootedness may stem from early in the diaspora when men began to borrow money from within the growing South Asian population community to buy homes (Shaw 2000, 51-2) rather than rent property (Bowes et al 1998). This money was interest-free as Islam forbids interest being paid on loans, but *lena-dena*[118] and *izzat* were almost certainly a factor in this process. That is to say the honour and respect for the lender would be much increased by this act. Equally, the borrower would be under an unspoken obligation to the lender. There would be a reasonable expectation that the favour would be repaid, with 'interest' at some future time. It is these early acts of generosity, by these men, which gave certain men high social status and which, in turn, led them to becoming community leaders later. From these events and from the large social/religious gatherings that occur frequently within what they describe as their 'community' the younger generations pick up many of the traditions and value systems.

[118] Defined by Shaw (2000) as 'taking-giving'

This sense of tradition and doublerootedness has an impact on all aspects of their lives, including the realms of health and illness.

Links to Pakistan are weakening but according to one woman I spoke with many [the majority] of the men and women in Riverside visit Pakistan quite frequently. For an inward looking, insular population they 'globe-trot' with consummate ease (see Gardner 1995; Werbner 1999). They often talked of a month in Pakistan much in the same way as one might describe a shopping trip to a nearby town or city. Many families offered to let me travel with them and their families '...next time they were going to Pakistan...' I could also stay with them and they would show me around their community,[119] whilst we were there.

One such example was Parveen who told me that she was going to Pakistan for a rest. The strain of her father's death and being pregnant was getting too much for her. Parveen said that when she goes to Pakistan she is '...treated like a princess...'. As her mother had left Pakistan, to live in the UK, her family had not been able to pamper her. So they were going to '...make up for lost time' by doing the same for Parveen. Parveen also mentioned that in Pakistan much of the 'normal' tradition of North Shore – particularly the wearing of the *hijaab* – was absent - '...They are much more modern in Pakistan...' she said. These linkages to Pakistani seemed to be of great importance, but often concerned aspects of a Pakistan long gone – an idealised world some fifty years out of date.

I spoke to two workers, a woman and a man, in a health initiative in Riverside about their sense of 'home'. From how they spoke of 'home' I had assumed, wrongly, that they were born in Pakistan. The woman corrected me; they were both born in the UK - the woman in Williamshore and the man in Cattleville. I then said that I had been thrown by her talking of '...*her* village...' in rural Pakistan and I had assumed that it was the place of her birth. She had described *her* village to me, as being only four houses. From this I had assumed that she had been born there and lived there long enough to have strong memories. I told her why I had formed the impression that they were born in Pakistan from their strong sense of Pakistan as 'home.' She thought on this for some time, then said that she had not

[119] Again their choice of descriptor.

realised that she talked of '...*her* village...' in Pakistan as if it were a reality. She was very surprised that a girl born and bred in Riverside could perceive rural Pakistan as her home, not Riverside. The man upon reflection also agreed that he saw Pakistan as 'home' even though he had never been there.

Yet, another family that I revisited in 2003 told me that what remained of their family in Pakistan had suffered much ill health and death since my last visit. The greatest problem was heart disease with several relatives, including the woman's mother, having had heart attacks. Her husband was still suffering from a 'bad back' and told me that many relatives had died in Pakistan, 'too many to return home for'. I suggest that this is a further clear indication that the links, and thus the doublerooted nature of ethnic Pakistanis, between the UK and sending society are weakening and, as one man told me, would end when his generation died out and did not want their bodies returned 'home'. I suggest that ethnic Pakistanis are moving rapidly towards what might be called fictive doublerootedness, which may become increasingly the case with each new generation born in the UK, and seeing themselves as British not Pakistani.

Gatekeepers:

By a *Gatekeeper* I mean a person or persons who are in a position of power with regard to an important cultural boundary and are able to control who may pass through – or not. These, relevant to this research, are most often members of minority ethnic groups who have acquired particular 'majority' skills such as training/qualification in community work or in the conducting of research projects concerned with 'minority' issues. I suggest that these gatekeepers have a vested interest in keeping control relating to their privileged access to *their* 'communities'. I evidence this assertion more fully later in the thesis. I read some of the documents produced from projects that gatekeepers have either conducted or been involved in informant selection. What may be clearly seen is the filtering process of the gatekeepers in these works. I have in many cases interviewed the same informants and been given completely different stories. The stories are often 'trotted out' to meet expectations or

legitimate claims for funding for the realms the gatekeepers' moderate. An example of this may be seen in some of the quotes attributed to informants in surveys done in Riverside (see for example Green et al 2003; Hills et al 2001; RCVDA 2003). What might be best described as 'the usual suspects' are often put in front of the researcher to evidence claims made by gatekeepers. Full access to the ethnic Pakistanis, by researchers, is often not possible as gatekeepers control access and time is short.

Riverside, and North Shore in particular, have endured more than their fair share of 'researchers' as they meet the criteria often specified by funders – poverty, urban decay, single parents and racism to name but a few. There are also two universities vying for research areas in close proximity. Yet few have managed to remain in contact with the local people, without gatekeeper assistance. I was able to manage to talk to a wider range of informants as I was both local and able to devote a longer period of time to my research. Later in the thesis I examine the wider milieu of gatekeeper activities particularly regarding the language myth.

But gatekeepers are not always successful. In North Shore Shafiul was the daughter of one of the local 'big men' and when he died she felt that she should assume the mantle of her father – continue the dynasty so to speak. She was working for the local borough council as a 'Race Relations Officer' and was able to persuade the council that she could both do the job and had 'clout' within *her* community, notably in the Standaira Community Centre, as she was her father's daughter. This was not the case and within a few months she had managed to fragment the South Asians in the area into factions (see also Cohen 1985, 34). After about a year even factions 'loyal' to her had become alienated. The council and the WEA diverted significant funding to the Centre, but to little avail. The ethnic Pakistanis abandoned (or were driven away from) their Community Centre in the power struggle that took place. A notable fact here is that if we take the information compiled by CCRI (1982a, 15), less than half the minority ethnic population wanted a separate Community Centre in the first place.

It was not only in the theatre of initiatives and projects that I found gatekeepers attempting to control the course of my research by controlling access to informants. I spoke to community leaders and [Islamic] scholars in the mosques in Scotland where I explained that I was attempting to get access to ethnic Pakistanis in the area, but I got the sense that they wanted to keep my findings limited to the 'official' line rather than lay opinion on the issues I was interested in. The people, in general, were felt to be lacking in knowledge and therefore not going to be of use to me. I tried, several times, to explain why I wanted lay opinion, but found that there continued to be a reluctance to give me access. I made my inroads in car parks and on street corners where I chatted to people about my work and got their views via that method.

Many gatekeepers, however well meaning they appear to be, like to maintain control of their constituents. At the beginning of my work, in North Shore, I was chaperoned by a community development worker who had been given time to work with me by her department. But as the months passed and I was no longer perceived as a threat by the ethnic Pakistanis I had met and it became clear that everyone I spoke to could speak English her role fulfilled more of a social role. The worker was more and more 'out-of-the-loop'. I noted in my field diary that on several occasions she seemed uncomfortable at times during the visits. I got the sense that she felt that she was being ignored, not only by me but the informants as well; her role was no longer central. I was told that her line-manager had told her that she should cease working with me. I suspect that the reality was that she was no longer able to control my access.

I suffered a much similar fate when another gatekeeper, Shafiul, realised that I did not need her patronage to gain access to the women in the North Shore and this provides evidence for my argument in later chapters. I had suspected that there was a problem with South Asian women accessing health care and this was confirmed by Chris, a Practice Manager in one of the GP practices. It was clear from Chris's contribution that she not only understood the South Asian issues but also had an empathy with the South Asian

population, perhaps more than some in the practice[120]. Chris suggested that there was a need to take positive action, specifically targeting the health problems suffered by South Asian women. Furthermore, Chris indicated that these initiatives should be directed towards the women themselves and not via the gatekeepers who may well be resistant to such initiatives as they fall outwith their own agenda.

First Cousin Marriage (FCM):

Here I revisit the original issue (consanguineous [first cousin] marriage), that drove my research. Whilst I was in Pakistan I had been told that FCM was practiced much less in Pakistan than in the UK. I had been told that the UK lagged behind Pakistan in the realms of traditional attitudes. That is to say the traditions practiced in the UK reflected a Pakistan of two generations ago, kept alive by the members of the Pioneer Generation, who wished to pass on traditions to their family. People I spoke to were not against marrying cousins '...it was allowed in the *Qur'an*...' and also '...the Prophet (PBUH) had married a cousin...' However [they said] few people did [marry their cousins] in the city; there was a wider choice of partners. They thought that it would be different in the villages, they were more 'backward' looking and there weren't so many people to choose from (Pakistan Field Diary 2000, 11).

On the return flight from Pakistan I met a medical student returning to the UK to complete his course. He was living with his brother in Coventry. We discussed the changing cultural attitudes to both arranged marriage and first cousin marriage both in Pakistan and the UK. He was surprised that first cousin marriage remained in any way a significant factor in the UK. He suggested that the move away from first cousin marriage was on the increase in Pakistan[121] and was surprised that people still came from the UK to marry relatives in Pakistan. We also discussed the possible genetic consequences of first cousin marriage. He

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[120] The South Asian head of the practice was the centre of many complaints voiced to me during this research. These complaints were made from all ethnic groups that I spoke with, not only those from the South Asian population.

[121] Rizwan, who owned the 'internet café' that I used to collect and send my e-mails whilst in Lahore, said the same. He told me that the practice of FCM was not common in either his family or his group of friends. He also mirrored the opinion that FCM '...might happen in villages...'.

suggested that socio-economic factors were a major influence on poor birth outcomes, rather than the affects of FCM to do with the risk from the adaptive mutation responsible for thalassaemia.

I related the story I had been told about the mother, in North Shore, who had been told, by a Health Professional, that her son's thalassaemia was the result of an incestuous union some generations past. His comment was 'Bollocks, genetics does not work like that'. He continued by arguing that the attitudes and perceptions of Health Professionals could have a significant affect on birth outcomes. This, he thought, was particularly the case if women were perhaps not offered the full range of diagnostic techniques either because of cultural stereotyping or simple economics.

I asked ethnic Pakistanis in the Cakestone (Scotland) about FCM – did they marry first cousins or from within *biradari* or outside of these categories? I was told by Rashid, an elder at the mosque: 'Not all, not all, some'. I then asked how many – half, more, less? I was told less than half of marriages would be to first cousins in Cakestone. Abdul went on to say:

> '…in this country there could be a little bit more, but in our country [Pakistan] not big much… very little… Err, because if a person comes in this country he wants to get his [children] married to [the children of] his brother's son. (Laughs) …to bring in this country… this away you know [conspiratorial laugh]… a bit of you err to give a little bit help … to his brother's son, to his family and that, this way… But back home is not big much…'

I then asked if one of the main driving forces behind FCM, in the UK, was to allow relatives to gain access into the country? He replied:

> 'This is one … one of the maybe, one of the maybe reason.'

Abdul continued

> '…Back home there not be much, probably in this country, yes, and bit more, back home is not very much. Because back home you got more choices' [all of the men laughed].

Another informant, Majid, told me all his married children, with the exception of his youngest son Tarik, were married to first cousins. When we talked of Tarik's wife, Frazan, Majid said 'she not my family'. I suspect that his youngest daughter will also marry outwith the family. Tarik said that he had chosen not to marry a cousin because he was British and so followed British tradition of marriage for romantic love, yet his wife came from Pakistan, not Britain. Frazan also has a degree, which she gained in Pakistan.

I have asked young people about marriage to a partner from Pakistan. The most common reply was to the effect that they would not like to marry a boy/girl from Pakistan '...they would not fit in here...' Another common comment was '…culture will be so different…'; it would be too difficult to get on with each other, and they 'wouldn't know what to do in the UK'. I also asked about marriage for 'romantic love'. Many informants said 'no', the arranged marriage is best. '...Once you are married you then have time to fall in love over the years...', was often quoted. Most said they wanted a partner with the same cultural values, someone who they could share UK life with. When asked whether they would consider a cousin they frequently replied that they would not like it to be a first cousin – many knew about thalassaemia from the television campaigns. Having said this most said they were not against a marriage within the family, it was allowed in Islam and it was also part of their culture.

Yet most parents still had much influence over children; they could manipulate the situation to fulfil their [parental] needs. I was told by one man that a daughter-in-law from Pakistan would be good as she would retain the tradition of looking after the parents in their old age. Unlike 'modern' children, born in Britain with British values, who would probably just put their parents in a home when they got old. A member of the older generation told

me he wanted his children to stay in touch with their homeland [Pakistan]. If they get married to someone here, they will not need to go back. Arranged marriages allow for a '…better chance that our children will be happy'. I was told by another woman that marriage with close family meant that they shared the same rules in the family. This meant less conflict and also you could '…give them a good hard slap…' if they did not do as they were told.

However, many informants have said that most [all] of their family now reside in the UK, which will add a further complexity to the issues but militates strongly in favour of the argument for the cessation of cousin marriage within the UK. The migrant generation identify fully with their homeland traditions but British born youngsters are not fully aware of these customs or beliefs because they do not regard the country their parents have come from as 'homeland'. For them it is simply a holiday resort – where they occasionally go for a few months. Arranged marriage and FCM are still high on the ethnic Pakistani agenda. Yet,:

> '…most parents have accepted the fact that they will have to consult with their children, before arranging a marriage…' (Razwan pers. com.).

It is this acceptance that may well allow arranged and probably first cousin marriage to survive for many years to come. Many young and educated women remain happy for their parents to arrange their marriages.

Two such women, both medical students, told me their views on marriage:

> 'With me it is completely different, the parents will have to choose the guy, I would not be allowed to see him before-hand. You know, just go out with him and say "Oh right mum I'll have this guy. It's more or less; she'll go choose someone who she thinks is appropriate for me. Then she'll ask me.'

I then asked Rahana whether she felt she would have the option to say 'No' to her mother's choice. Rahana replied

'Well yeah, but if she like, well at the moment she's looking for an educated guy and if she really likes him and thinks "Yeah, he's going to be a doctor as well" then, then yeah she's gona like keep on harassing me about it basically, put it that way. It's more kinda like force as well, that way I think.'

I then asked whether she would accept the 'force'. Rahana replied

'...In the past a lot of like my cousins, they have. So I think I'm gona *have to* really, at the end of the day. I think I'm going to have to finally accept it. It's one of those things; you have to do it cos everyone else does.'

I then asked the other young woman for her view on arranged marriages. Tasmin replied somewhat timidly:

'I would say that arranged marriages are very good, I'm quite for them [Laughs]. But, errm, I think it's a wee[122] bit different as in that they [her parents] are quite happy for me to choose somebody myself. And then if I say "I like him" they are quite happy for me, for them to arrange it from then on - as long as I don't have any contact with him. But like if I know of him through other people, or anything like that, they're ok with that. But if I don't find anyone myself then they will do it themselves. I'm not too bothered if they choose, I'm quite happy with that. I'd rather they chose actually [giggles] than have to do it myself...' (cf. Shaw 2000, 8).

This seems to confirm what I have been told both elsewhere in Scotland and in Riverside - arranged marriages are likely to continue for at least the next generation. Local and family pressure would seem to be the driving force at work in perpetuating this custom – much as the media would have us believe. However, these women demonstrated that even with the much more flexible and 'free' milieu in Scotland they would prefer a marriage

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[122] Whereas Rahana had a 'townie/South Asian' accent, and style of phrasing not too dissimilar to that common in Riverside Tasmin has a cultured and clearly Scottish accent. That is to say if I had not met the two women face to face I would have identified Rahana's ethnicity from her spoken communication (the same could not be said of Tasmin). This was perhaps the very first thing I noticed in Judderstone when I heard my first 'South Asian' speak. I would argue, this clearly demonstrates the differing levels of assimilation between the English and Scottish communities of Pakistani origin.

partner chosen and arranged by the parents. Thus I would argue that for many the tradition is as strong as ever and is not one enforced by pressure, social or otherwise, but rather a freely chosen pathway.

But all is not contentment with ethnic Pakistanis in the UK. I spoke to another young woman, Ruksana, in Riverside who had a very different perspective. She told me:

> 'Well, I don't think I'd agree with it [FCM] because, well, because I don't, I don't really like the idea of first cousin marriage. It's a bit like, like a bit too close to the family.'

Her friend Julie commented:

> Well in my family I don't think there has ever been a first cousin marriage, as apart from a few families that we don't even talk to.'

She gave a nervous laugh and told me that her mother and father were not first cousins and that both of her grandparents had made '...love marriages[123]...'

I met one of the community leaders to get his views on FCM in Riverside. He told me that from his arrival, in 1958, to the nineteen-seventies the rate of FCM in Riverside would have been around 90% of all ethnic Pakistani marriages. Between 1970 and say 1995 this rate of FCM would have dropped to around 50%. Between 1995 and the present he would say that this figure would have dropped to less than 15% of marriages. He told me that girls now wanted to marry by choice and predicted that FCM would be '...almost totally gone within the next ten years...'

This view is supported by the comments made by Dr M and many other educated ethnic Pakistanis in Riverside, and is also, supported, to some extent, by my observations throughout the research. However, there are also equally strong statements from other quarters that the tradition of FCM will continue in their family 'forever'. Only time will tell

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[123] There has been some comment [by tutors at my previous department] that the term 'love marriage' is in some way condescending or not 'academic'. I disagree, the term is understood, and widely used, by all of those that I have talked to over the five years that I have been involved in this research. My position is that if the informants are happy with the term then I will not attempt to overlay my western value systems on their culture – I feel strongly that such value judgments [by outsiders] are at the root of the issues that this research highlights as being problematic. Also see Donnan (1988, 208).

as to whether this is indeed the case. There have been major changes in the attitudes of many ethnic Pakistanis in Riverside, which is reflected in Scotland also – even over the period of this research. For example one man, when we first met, said his daughter would marry his best friend's son from Pakistan. The two men had arranged it as soon as the girl was born. When I asked him some three years later if it was still his intention he said it would be up to his daughter, she would decide if she wanted to marry and to whom. He continued: '…y' can't force ya kids to marry no more… they must 'ave choice nowadays' This was mirrored many times in my conversations with parents, and also several young men said that they would decide on their partners, not their parents.

This view was not held by all. The community leader suggested that many of the men from the older generation in Riverside still held the views that they had back in rural Pakistan. So there was much conflict between them and the younger members of their families. The men wanted to continue as if they were still living in the Pakistan they left fifty years ago. Their children, and often now their grand-children, were born in the UK and their experience was much different. They were more westernised and wanted to do things their way. He said that he often had to mediate in such disputes over marriage customs. The one factor that unified the generations was Islam. He told me that many of the older men would say that you had to marry your cousins '…it says so in the *Qur'an*…' He said that he would point out, often with the support of the Imam, that the *Qur'an* said you could marry your cousins, but not to do it too often.

I had a very similar conversation with a *hafiz* at one of the larger mosques I visited. He told the assembled group of men:

> 'If you keep continuing marrying first cousin it is in the Prophet's sayings [*Hadith*] that if you marry continuing the first cousin there is a possibility there is a disabled child.'

It was clear, from their body language and facial expressions, that there was a conflict with the group's 'traditional' view of FCM, which in turn they thought of (and I think believed)

as being Islamic, and what the Imam had said. This conflation of Islam and South Asian tradition with regard to FCM is common among the majority of those Pakistanis (and the most common view among the men). I have talked to during this research. One of the men, Abdul, continued by telling me that, '…the Prophet Mohammed (PBUH) he say it is better for you to marry… far [Iman interjects "distant family"] instead of first cousin, is better.' Abdul put an emphasis on the final part of the sentence. The Iman spoke perfect English, with little [South Asian] accent, in a very soft tone of voice and added:

> '…because there is less chance, there is no chance, to make a deformed body baby… You see? That is the sayings of the Prophet (PBUH)…'

Abdul continued:

> 'The Prophet says "OK, you can marry a first cousin but don't keep it going and going. If you are still going and going then there is a chance of disability." But, but he advise that "OK, you do, but try to do it from a remotest family".'

Again the Imam interjected to explain and clarify the point he wanted to be made:

> '…If you keep marrying the first cousin then your thinking power is lessened. Your genes become very close and this leads to a weakening of the mind - if you're marrying first cousin, first cousin, first cousin. But if you marry the remotest family, or outside of the family altogether, rather than cousin family is best.'

The Imam made the Islamic perspective crystal clear, but equally clear was the men's resistance to the message given.

According to one woman, Ruby, who I talked with, the poor birth outcome does make first cousin marriage bad idea. She went on to say:

> '... It may be okay for parents, and the culture, but not for the child who has to spend many hours in hospital being asked awkwardly embarrassing questions by doctors...'

I got the very strong impression that she was such a child. She continued:

'... The thought of a marriage to a first cousin makes me feel sick...'

I asked why this was this? Ruby replied

'... It [FCM] might be okay for somebody, but not for me...'

Generational differences:

There is a popular myth that 'Pakistanis', born and bred in the UK, are in some way suffering from having to live their lives in some way between cultures – Western by day in their work or educational activities and traditional oppressive lives when they return to their family home. This presupposes that ethnic Pakistanis are in some way unique in living in different realms in different segments of their lives. We all, whatever our ethnicity and particularly those with families, adopt various roles - parent, student, nurse, chef, economist and sibling - without any apparent major conflict or problems. This ethnocentric assumption often made about 'British Asians' is further compounded by suggesting that only northern European norms and values are the acceptable ones. I suggest that integration is taking place within this population – if only the state is able to come to terms with the axiomatic reality that 'they' are British in every sense of the word – not alien, not 'other'. Here I attempt to show how the ethnic Pakistanis view themselves and how problematic audit culture makes this reality.

One of the greatest complaints from the older generation was the disrespect shown to elders by the younger generation. I was told by an Imam of a small mosque in Riverside that there was a growing lack of respect for the older generation from the ethnic Pakistani youngsters. He said that when young men and boys came to call on him they used to call him 'Uncle Rashid', now it is just plain 'Rashid'. I spoke with one Pakistani shopkeeper in Scotland who told me that he did not like living in the UK and wanted to go home [to Pakistan]. So I asked him why he did not like the UK. He paused for a few seconds, and then answered: 'I don't like how the kids are in UK. They are too Western, they have no respect for elders anymore...' I asked him what he meant by that. He went on to explain that

the young no longer held the same values as in his day. He said he wanted to teach his children

> '...like that... But they ...don't do... 'cos they're look like British people... they are like British. My youngest daughter she exactly like British. Oldest daughter has little bit culture because I take her Pakistan I show to her the family and she bin twice, three times and she stay over there five, six month then she understand what is the respect.'

In North Shore I encountered another very strong, very *British* Muslim woman, Sabeeya. This encounter was also indicative of a change in attitude from the younger generation. This more 'Western' less polite interaction is, I suggest, one of the strongest indicators that this group see themselves as quite unashamedly British. The older generation had a deference to the Raj and respected 'all things British [English]' and wanted to avoid conflict. The younger generation are much more likely to contest their situation and demand their rights as UK citizens, born and bred. The old social controls are much less effective in holding the younger generation into place. This new found confidence has an impact on how the NHS needs to modify its approach to minority ethnic groups if it is to achieve its aims and objectives to provide healthcare for all.

A very much more forthright ethnic Pakistani view was demonstrated by a younger man in Riverside. Mohammed's persona was very much the stereotypical 'Sun Reader' when referring to the 'Third World'. Even though he is culturally Pakistani and Muslim, he holds views on 'foreigners' not too far apart from what one would expect from members of the National Front or British National Party (BNP) on 'foreigners' coming into the UK. He believed:

> '... They shouldn't be let in; they pinch our jobs and sponge off the welfare state [NHS]. All [Britain's] problems stem from their ['foreigners'] ...invasion into the UK... The government should stop it... this would solve all of Britain's problems...'

One of the big changes Julie, a young Muslim woman from Riverside, reported was that:

> '…Some youngsters even succeed in westernising their parents to the extent where they allow their children to marry someone of their own choice – not caring what race they are, as long as they [the marriage partner] are prepared to change their religion [to Islam]…'
>
> Clearly Mohammed did not have the monopoly on stereotyping. Julie continued:
>
> 'It's like my sister; she was on work experience at Pizza Hut. She's been there for a week and a half and they offered her a job. She goes up to them [teachers] and says guess what, "I've been offered the job"…
>
> Her teacher said "Are your parents all right about it?" She's like, "Of course they are, why wouldn't they be?" Teacher: "Right... No problem"...'

She also told me about four or five people (customers in Pizza Hut), who asked her sister:

> 'Are your parents all right about you working here?" [Laughs] I was shocked when she came home and told me. [Laughs] It shows that people do actually mix culture with religion, they are completely opposite.'

Both women perceived themselves to be British and were surprised that others did not share their view.

> I asked others how they thought of themselves. One young woman, Tasmin, said:
>
> 'Well, I'm a Pakistani, but a Pakistani born in Pakistan's understanding of 'Pakistani' is really different…. I'm more modern. Like the old-timers are more really into traditional things like arranging marriages and girls don't go out to work, girls don't go to university. But like I'm ok, I'm at university here.

Her friend, Rahana, continued:

> 'It all depends on what part of Pakistan you come from, like with me I'm more like a village type. You're, she's more of a city type so they're more like modern.'

I asked where she was born, was I mistaken with her accent? She replied:

'I was born 'ere [Manchester]. It's my parents that were born in Pakistan'.

I asked which village they were from. She replied:

'Err, you have not heard of it, it's called Mirpur.'

I asked if it was the city or a village in the province. She replied:

'It's more of a village. Yeah, that's what I meant.'

I then asked the name of the village in Mirpur. Shabnam replied:

'I don't know.' [Laughs]

Here 'village' is used as a trope for a claimed traditional rural background, rather than a physical location.

I asked a young Muslim man at a Scottish university how he would describe his ethnicity. He replied 'Pakistani, I'm Pakistani.' (Note: Nasir had a fairly strong Scottish accent, suggesting he was born in the UK. Later in the interview he said he was born in Cakestone.) After further discussion on other research related topics I returned to the question of felt identity. Did he see himself as Pakistani, British, Scottish, British Asian… He said:

> 'I just see myself as Muslim, for a start. Because I [pause] in Islam we don't have a concept of nationality cos we believe that it just disunites people. And there is like a *Hadith* of the Prophet (PBUH) that said err "Leave nationalism, it's rotten – because it disunites people." And therefore I just see myself as Muslim.'

An interesting change of position – when he realised that I wanted to talk about Islam he changed his self-image from 'Pakistani' to 'Muslim' – remembering that '…nationalism is rotten…'

Another young man, Neebeel, who I spoke with told me he had been to Pakistan three times in his life. When he was there he said he had to wear *shalwar-qamis,*[124] he did not like it. He preferred his western clothes. After all '…he was born in Britain… he was

[124] Loose fitting trousers and shirt.

British…' He and his wife and their two children had moved out of his parents' house in Cakestone and now live in their own home in Swanarc. I asked why Swanarc, he said he wanted to move out of the 'community' in Cakestone and live his own life. But still be close enough to relatives to visit – Swanarc is about a twenty minute drive from Cakestone.

I was talking to a group of men in a mosque in Central Scotland one day. Two of the men were father and son. Both saw themselves as 'modern', that is to say Western. Mr C was proud to be an English Pakistani – he was born in Manchester. However, his son said quite unequivocally that he was Scottish. They both held self-images that were more British than Pakistani. Thus their self-image was at odds with the perception held by many non-Pakistanis. If this perception, which is clearly false, is held to be the norm by Health Professionals then interaction between the two sides will be at best difficult and at worst disastrous. Here is a clear mismatch between phenotype and social corporeality.

In discussion with one of the older generation about links to Pakistan, he said that his father and grandfather were both dead and most of his brothers and sisters all now lived in the UK. He returns to Pakistan to see friends and the few family members that remain in Pakistan. His son (he has one son and one daughter) also lives in the UK. He said that his children might go to visit Pakistan once every three or four years: '…much less when I go from this world…'. He did not expect that his grandchildren would ever visit Pakistan: 'They born in the UK and see that as 'home' not Pakistan'.

For this reason links to Pakistan will, according to him, become:

> '…very less and less and less… until there will be no links…' He continued
>
> '…The new generation coming up will be little contact no… Like same as the people settled in America, you know, they are all Western, they are Americans. They hardly goes to Pakistan. Their father and grandfather go maybe once or twice, but to them [the children] it [Pakistan] is a strange country.'

One of my friends was telling me that his children were losing their culture – by which he meant losing *his* Pakistani culture. He was concerned that his son tells everyone he

is British. He said to him: '...you black British...' Ruhul said 'No, just British!' His son does not mind going to Pakistan '...for a holiday...' but home is in the UK. Both he and his older sister are keen on football and support Manchester United – not an unsurprising choice. Both children told me that they play with their English friends and go to their houses to play. They also have a friend who is ethnic Bangladeshi. His father told me that the Bangladeshi family are his children's adopted family. This again supports my contention that to think of the majority of 'Pakistanis' in the UK as anything else but British is a mistake.

Part Three

Risk Measured and Mapped

Introduction to part three:

In the next three chapters I consider the processes by which risk is measured and mapped. By this I mean that risk is measured, and then ascribed, via the overarching audit culture in Britain. The mapping is the ever increasing plotting of individuals via their DNA in the screening processes that is becoming increasingly common place with regard to human reproductive technologies. The twin trajectories of audit culture and the new genetics form a double helix are claimed to empower the lay individual in the medical encounter. However I argue, this transfers ever greater responsibility from the Health Professional to the patient. This is often performed in an increasingly politicised milieu, where rewards and sanctions are dependant on outcomes being achieved and thus audited boxes are 'ticked'. The auditable element of this process often comes in the guise of initiatives. Although Alexander (1999) found that initiatives had very little impact, and the Department of Health agreed, still more initiatives with concomitant protocols and guidelines become ever more pervasive. Systems of control are so powerful that individuals feel powerless to resist – leading to an ever greater Panopticon effect. I also look at how the language myth is constructed and performed in the spaces between the ethnic Pakistanis and Health Professionals.

CHAPTER SEVEN

RISK AND AUDIT

The red thread of risk is continued into this chapter, but is interwoven with two major themes – audit culture and the New Genetics. I suggest that this combination offers some insight into differences in service provision,[125] to ethnic Pakistanis and argue that in health care provision it is motivated individuals, not best practice, that are moving forward progress in relation to seeking solutions. Furthermore, I argue that audit increases both individual and population risk in several significant areas. These perceptions of risk are explored via the tensions and similarities between the New Genetics and audit culture. I argue that the continued culture of audit fails to exculpate the charge of institutional racism within the NHS. Rather as the NHS attempts to become more 'patient centred' and continues to develop best practice in order to meet politically set targets it does more harm than good. One of the key areas I identify in this respect is communication - particularly the claimed language barrier between the two sides.

I began by talking to Health Professionals about how their job had changed, particularly since audit culture had become *de rigueur* within the NHS. It became clear that most of the people I spoke to seemed to have 'taken-a-step-back' from their job. Let me try to explain. My social expectation is that doctors and nurses make people well – they are caring and person centred, perhaps a little bit frightening, perhaps 'bullying' you into getting well. They are clearly motivated to doing their very best to make you well, whatever that takes. I think what I am saying is that we view them as the caring professions. However, with the Thatcher Revolution Health Professional practice became increasingly overlain by procedures and protocols and guidelines; things began to change. Resisting these incurs sanctions – working outside the box is no longer a desirable trait. Going the extra mile has

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[125] Not only are there differences in provision between the two countries, within the UK National Health Service (NHS), but I suggest that there are significant difference between Health Regions within the two countries.

come to be seen as a little foolish, you only get paid for what management wanted you to do, and no more. Slowly, slowly people have to become more and more 'jobsworths' – a derisory term in my youth, now, re-badged, it is a desirable trait. By the time I began my research, this ethos, I suggest, had become enculturated into the workforce. It was by then so ingrained that I was frequently told that the fear of litigation was one very good reason for compliance with guidelines and protocols.

When I spoke with the medical students I asked them about ethical issues around informed consent. The students had told me there was an 'ethics' question at the interview for a place on the course. I had also been told that ethics was a big part of their training. A female third year medical student said:

> 'To get into medical school there's always an ethics question. So you always read-up on one to prepare for the topic. So you know a fair amount before you come to medical school. You know the *standard answer*, to get you into medical school. Whether you *believe* it or not believe it is just not the issue. The point is to get into medical school you're telling them what they want to hear'.

The student continued her train of thought:

> 'Perhaps by telling them what they want to hear so many times, by rehearsing it you then *accept it* as the norm. Which is then reinforced in your [laughs] ethics course. [Pause] Errm, so I think it is difficult for me to say. Perhaps I didn't come to my conclusions on my *own* but as a matter of course because of the career I have decided to pursue errm [pause]. It's quite an interesting point actually, isn't it [nervous laughter]. Whether I believe in the things I believe in because I've been programmed or whether I actually believe them. I don't actually think I even know… well no I don't think I could actually [pause] as opposed to the other outcomes…' [tone here was reflexive]

So after just over two years of enculturation a bright, quite self-opinionated individual, when questioned, realises that she had changed – and has, perhaps, become a person that she herself no longer recognises.

Informed consent revolves around the idea, now increasingly stressed, that patients, not trained/skilled professionals, should be asked to make medical decisions about their care – patients have become participants in, not just passive receivers of medicine. I often felt that Health Professionals were resultantly passing on life and death decisions to their patients – and avoiding the responsibility for their own action or in-action. Here was an example of a 'double-helix', where risk perception and audit intertwined. A second year female student at no time saw she would have to entertain risk relating to patient care – she would have done her job if she has told the patient all of the 'facts', a position no different to that taken by qualified Health Professionals I had talked with. Taking this position, after full disclosure of the facts the risk, in every sense, is the patient's – the Health Professional has achieved a 'safe', and auditably sound, position. It is the patient that must assess the risk and live [or die] with the outcome of that risk. One might argue that a second year medical student is not qualified to deal with my questions. I would disagree. She will not be made more humane by the next four years of her training – quite the opposite. She will become more enculturated in to the audited culture that is the modern NHS.

I asked one of the GSMs about informed consent and how protocols and guidelines impacted on this. My thoughts on listening to her answers led me to ask whether by trying to be even handed and give an unbiased stream of information she might not be doing her best for the patient. Perhaps it might be more patient centred to describe the alternatives to success more clearly. Perhaps explain that an 80% chance of success carries with it a very real 20% chance of failure. The process of professionalisation and compiling auditable evidence trails covered her against possible litigation or sanction and she could 'demonstrate' informed consent (via a signed consent form), but had she achieved it? Lay and professional understandings of risk are often very different – I felt that very often the

Health Professionals assumed that patients understood what was being told to them when often it was not the case.

A related issue is the demand from politicians that there should be auditable and measurable improvements year on year (health as a business) in patient care and patient centred medicine (also *evidence based*[126] medicine). It was felt, by the vast majority of the Health Professionals I talked with, that this system, although it was said to be done with the best of intentions, was quite often counter productive and increasingly limited the opportunity of patients being treated as individuals. Iatrogenesis by audit?

There is a second matter about audit and risk relevant to the importance of guidelines and protocols. Foucault's idea of the medical gaze (Foucault 1976) stresses scientific rationality in modern medicine with the emphasis on the objective and numerical measurement of physical and psychological states. But this yields the depersonalisation of the patient and reveals patient-centeredness as a chimera - modern medicine is dualistic. It tends to split mind and body (Helman 1990b, 19), perceiving physical and chemical data as more 'real', that is to say clinically significant. This is particularly the case when measurements are taken using diagnostic technology (ibid). Genetics fits this pattern to perfection. This can be juxtaposed against the lay world view which tends to be subjective in the sense that a personal view of 'unwellness' informed by the experiences of family and friends gives meaning to the illness (Helman 1990b, 20). Genuine patient centredness would focus on this holistic fact.

So it is that the audit structures set by the NHS, or rather those enculturated within it, have become even more powerful via the use of DNA tests. Control of the patient is thus established not only in the seen realm, via performance criteria, but at the invisible, but inevitable core of their very being. Here the patient loses agency and is powerless to make any change, for their DNA is inescapable. Women are routinely screened for the haemoglobinopathies, almost entirely without their knowledge. Once an anomaly has been

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[126] That is, diagnosis based entirely on measurable/auditable evidence. No longer is experience or intuition to be involved in the process. See Smith (1992).

identified it is largely too late to put the gen[i]e back into the bottle. Ethics relating to informed consent takes a back seat, technology rules supreme, for it fits with the medical or disease model enculturated into the Health Professional. The patient is reduced to a mere set of physical symptoms by the technology. The doctor, suggests Helman (1990b, 20), may then be oblivious to the origin, presentation or prognosis for the patient's ill health.

All told, I will argue that audit uses the science of the New Genetics as a tool to justify practices which are both self-promoting and self-perpetuating. The state uses the technology of audit to control at arm's length (cf. Shore & Wright 2000). This technology uses risk to perform[127] the very people we are told are being allowed to self-actualise due to the empowerment given by audit. Genetics is arguably a new and selective scientific racism. It has been frequently suggested that genetics and eugenics are interchangeable (Genewatch 2003; Winston 2003). I am reminded of a line from *Gattaca* '...we now have discrimination down to a science...' (Columbia Tri-Star 1997). But who might be at-risk in the here and now from audit? I am not alone in seeing that best practice merely brings all performance down to the lowest common denominator – the 'dumbing-down' of society which has exercised commentators for the past decade. People are afraid that if they step outwith the guidelines they will encounter litigation. In fact the Panopticon has, in this respect, become a reality. Audit is, arguably, the Panopticon made real. The risk inherent in such technologies is both pernicious and far reaching. In noting that audit is about systems of control, Strathern (2000) concludes that it has little to do with the practices that are being audited. I believe the risks here are axiomatic.

Audit measures and maps human interaction; however, genetics measures and maps the very building blocks of human beings. The combination of the two structures allows for the potential to audit the individual at the very essence of their being. The two technologies are now so intertwined that it is often difficult to see where one ends and the other begins. The issues that I consider below demonstrate how the performance of these technologies disadvantage both

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[127] What I am suggesting here is that individuals, to some extent, have agency, which is the ability to affect their environment – that is to perform their world. I argue that the hegemonic nature of audit and the inescapable doom of DNA acting in concert to perform individuals, making them act go against their own chosen interest – to be performed. (See Moser & Law 1999, 196-219; also Law & Hassard et al 1999) for a fuller discussion of this concept. In essence Baudrillian simulacra (see p 17-19).

sides studied in this thesis and have implications for interactions throughout the wider milieu, both now and in the future.

CHAPTER EIGHT

AUDIT, CONTROL AND THE LANGUAGE MYTH

Audit Culture:

Many commentators have found audit culture problematic. It is my observation that the intellectually bright have tried to perform audit and have had their 'wrist slapped' for their trouble (cf. Shore & Wright 2000, 75-6). The intellectually weak are performed by audit – it has been said that the meek would inherit the earth – perhaps they were right? There is little doubt that the 'auditors are now running the asylum'. The constant 'dumbing-down' of services to the lowest common denominator is not good for society in general or ethnic Pakistanis in particular.

It is my contention that audit culture within the NHS, and wider interlinked initiatives, leads to institutional racism and a poorer service for minority ethnic groups in England and Scotland. Furthermore, I argue that, even though there is a national screening programme for the haemoglobinopathies in the UK, it is personal interest, commitment and motivation on the part of individual practitioners that make the service effective, not a national political will. I found this to be the case in both Riverside and Central Scotland.

Throughout this thesis I talk of protocols or rather report that my informants talk of them. This word is a typical piece of audit culture. As noted in the first part of the thesis, it suggests that every human action or process can be reduced to a flow-chart, similar to that used in the design of a computer programme. Once these protocols are in place, they become 'set in stone' – like a piece of computer software - unmoving and immovable – with no place for humanity. If the protocols are not followed, then sanctions are in place to 'encourage' compliance. One of the most frustrating aspects of audit is that nothing outwith the protocol can be discussed. This state of affairs I strongly suspect is one of the reasons for an increase in violence towards NHS staff. The inflexibility (lack of the expected caring element of the interaction) of the NHS staff who have been enculturated into fulfilling

performance criteria and making no exception make people [patients] feel powerless (cf. Smith 1992).

Audit is, in theory, a fine philosophy – which is not borne out in practice. Many of the Health Professionals I talked with told me of a sense of ill-ease and of covert threat linked to audit. It was pointed out to me, more than once, that guidelines were much more ridged than the word suggests. Stepping outwith the guidelines most often led to some form of sanction against the offending individual. This also had an effect on my research as often people were worried that I would find them in some breach of protocol or betraying a sense of uncertainty in their answer, as they were not certain which performance criteria were being evidenced.

Despite the professed aim to put the patient at the centre of the process, little has changed for the better. A prime example of how the patient remains a secondary concern is evidenced by the remarks made by Dr Ian Bogle, outgoing chair of the BMA. In his final speech at the BMA conference, in Torquay, he said the NHS was involved in a political trajectory to manipulate figures and fill 'ticky-boxes' to meet government set targets (BBC One O'clock News 30/6/03). Clearly I am not the only commentator to see the present situation as problematic. Several GSMs and midwives told me that they felt that the system, although done with the best of intentions, was counter productive and increasingly limited the possibility of patients being treated as individuals. In a sense they were saying that the more time that is spent on achieving these 'improvements', or rather completing ever increasing mounds of paperwork to demonstrate the systems were in place to deliver performance targets, the less time there was for the actual interpersonal contact with the patients.

In this thesis I show that the use of audit and initiatives that have been claimed to have the aim of giving 'equal access to health' for so called minority ethnic groups have, in the main, constructed and performed risk. To begin with, audit requires a set of definable and measurable targets. As we shall see, one solution to meeting this need for audit is to channel

resources via gatekeepers – usually community leaders, often men in the case of the patriarchal culture that describes ethnic Pakistanis in Britain – thus allowing the NHS to access these 'difficult' groups[128]. One of the key justifications for this process is the myth that language is an issue for this group, that is to say there is a belief, among many of the Health Professionals I have talked with that ethnic Pakistanis can't speak English or they need translation of documents and interpreters for oral communication. There are also very real risks with this process, notably mistranslation, or, more problematically, edited versions of the exchange mediated by cultural norms and expectations. I argue that informed consent can not be achieved and positive harm can result from this miscommunication process.

It is my belief, based on the evidence I have gathered over the past five years, that individual racism, although it must exist as Health Professionals are drawn from the population at large, is not a factor in failed initiatives to the Pakistani population. However, I do argue that institutional racism, often the result of audit culture, is a major problem in the NHS. I open up this issue via the narratives of the people who work within the system.

Blame avoidance as a cultural norm or Stories from the Human Genetics Commission (HGC):

According to its website (http://www.hgc.gov.uk), the HGC is the UK government's advisory body on how new developments in human genetics will impact on people and on health care. Its remit is to give ministers strategic advice on the 'big picture' of human genetics with particular focus on social and ethical issues'. I have not met the individuals who are members of the HGC and my stories come from the minutes of the meetings that are published by the Government on the internet. I have applied my historian's skills to the documentary evidence to hand. I shall show that HGC advice concerning the matter of genetic handicap is dogged by audit culture.

This story has as many twists and turns as any piece of history that I have pursued in the past. The adventure began innocently enough with the literature search for this thesis. I

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[128] I suggest that these approaches encourage continued 'ghettoisation'. I further suggest that this is a two way process, with vested interest groups, on both sides of the ethnic divide wittingly or unwittingly guilty of perpetuating this process.

found a consultation document entitled 'Prenatal Genetic Testing' which I printed out and 'filed' for later review. This document was by a Quango[129] called the Advisory Committee on Genetic Testing. When I became involved in the writing-up process I decided to get the final version of the document – post consultation. I had a reasonable expectation of finding such a document on the government's web-site – but there was no final version. All that could be found was the consultation document that I discovered some years previously – but published by the HGC. I then entered into a bit of sleuthing. I was curious as to why the document had never moved beyond consultation and why it had been formally published, apparently as the only document that the state offered as guidance for prenatal testing in the UK.

There are several important issues that need to be clearly defined with regard to abortion of foetuses – the preferred 'cure' for thalassaemia. Health Professionals look toward the HGC for guidance – but all that is to be found is the consultation document previously mentioned. I will now look at the progress of this document and try to demonstrate how my description of audit culture is evidenced. The first problem is the Advisory Committee on Genetic Testing (ACGT[130]). Half way through its life it was disbanded by the government and replaced with HGC. However, there was no continuity and nor were HGC personnel transferred to the new body. In what can be best described as a Pythonesque flurry of feathers the advisory committee was no more, it was an ex-quango.

In 1998 the ACGT set up a subgroup, the Genetic Testing Sub-group, to look at the issues of prenatal testing – which led to the consultation document. But before the consultation process could be completed the ACGT was '…subsumed into the Human Genetics Commission….'[131] There then followed much discussion, the first such at a meeting held on 13/06/00. This HGC meeting was held three days before the consultation process was due to end. The consultation covered Health Professionals and '…other relevant

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[129] Quasi-Autonomous Non-Governmental Organisation – a by-product of the *Thatcher Revolution* and arguably the bastard parent of the audit culture that blights the *developed* world today.
[130] Same initials as the four bases that form DNA – coincidence?
[131] http://www.doh.gov.uk/genetics/pgt_intro.htm

organisations such as patient interest groups, including the Genetic Interest Group[132]...'[133] Comments were sought from the HGC committee on the requirements for dual accreditation under the Clinical Pathology Accreditation (CPA) scheme and also ISO 9002[134]. There was further discussion of 'quality systems' and External Quality Assessment Systems (EQAS).[135] Note that the above are all concerned with compliance with standardised performance criteria for laboratories licensed to conduct DNA tests. There appeared to be more concern for these accreditations – in short audit culture - than for the human and ethical aspects involved.

But at this HGC meeting there was also some discussion about the need to examine ethical issues. It was suggested that the document placed too much emphasis on the clinical profession acting in the best interests of the woman, but gave no indication who would act in the best interests of the unborn child. There were also some committee members who felt that there was too great a presumption that a pregnancy would be terminated following the discovery of an abnormality.[136] This group agreed to meet again in July 2000 to consider '...wider social and ethical issues...'[137] It is clear from these minutes that the major concern of this group is directed at the construction of an auditable evidence trail with social and ethical issues taking second place.

At the meeting held in July 2000, again the primary concern was quality assurance and the need for practical guidance for the NHS[138]. The key terms of audit culture are present – setting standards and promoting best practice. But there is nothing of a patient centred approach in a text that will become the 'bible' for prenatal testing in the UK. At this meeting the group decided that the HGC should; '...consider in detail the social and ethical

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[132] Genetic Interest Group is the national alliance of voluntary organisations with a membership of over 120 charities which support children, families and individuals affected by genetic disorders and their families.
[133] http://www.hgc.gov.uk/subgroups/genetic_testing_13june.htm Section 4.1
[134] ISO 9000 and 9002 are quality assurance protocols which were designed for manufacturing processes and subsequently 'applied' to non-mechanical processes in the early stages of audit culture .
[135] http://www.hgc.gov.uk/subgroups/genetic_testing_13june.htm Section 4.2
[136] http://www.hgc.gov.uk/subgroups/genetic_testing_13june.htm 4.3
[137] http://www.hgc.gov.uk/subgroups/genetic_testing_13june.htm 4.4
[138] http://www.hgc.gov.uk/subgroups/genetic_testing_27july.htm 5.1

issues relevant to the whole area of genetic testing…'[139] The committee however, felt that it would not be able to do so '…until next year…'[140] This meeting also noted that the document talked of testing and not screening and the differences should be made clear (see page 78-9). It was agreed that diagnostic ultrasound was a form of screening and that with increased accuracy there was a likelihood that defects would be even more likely to be discovered. It was suggested that people [patients] be fully informed regarding anomalies that could be discovered and what this could mean.[141]

It was felt that the report should flag-up ethical issues, but made no comment on them. Although it was also thought that there should be provision for support for those [patients] who decided to continue the pregnancy after the discovery of a genetic defect, as for those who decided to undergo termination of the pregnancy. So a meeting that was to consider social and ethical issues did very little to that end.

At the HGC meeting of 12/01/02 the avoidance of 'grasping nettles' begins in earnest. One committee member disagreed with the World Health Organisation (WHO) definition of 'serious handicap' being used in the report.[142] Though the same definition is also used by the Royal College of Obstetricians and Gynaecologists (RCOG)[143] it was felt that the guidelines should be updated by RCOG[144]. In section 6 of the minutes of this meeting HGC said it was '…not appropriate...' for HGC to publish the Prenatal Genetic Testing report as it was not authored by them. If you recall, the ACGT was subsumed into HGC in 1999. The Department of Health (DoH) was said to be looking for other ways to publish the document, which was '…taking longer than expected…'[145] One such route, it was thought, might be via the National Screening Committee (NSC), and a meeting with its

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[139] http://www.hgc.gov.uk/subgroups/genetic_testing_27july.htm 5.2
[140] http://www.hgc.gov.uk/subgroups/genetic_testing_27july.htm 5.3
[141] http://www.hgc.gov.uk/subgroups/genetic_testing_27july.htm 5.3
[142] http://www.hgc.gov.uk/subgroups/genetic_testing_12january.htm 5.7
[143] RCOG (1996) Termination of Pregnancy for Fetal Abnormality (London: RCOG) 3.3.2, pg. 6-7
[144] At the time of writing I am unaware of any such update. My copy of Termination of Pregnancy for Fetal Abnormality was supplied directly from RCOG when I telephoned them to find their views on the matter.
[145] http://www.hgc.gov.uk/subgroups/genetic_testing_12january.htm 6.1

Antenatal Sub-Group was arranged.[146] When they met, they also declined to publish the document[147].

Nobody it seemed wanted to have their name linked to the document. Everybody agreed that it needed to be published. Everybody agreed that there were major issues which needed to be addressed. Everybody agreed that there was a need to make clear definitions on which decisions could be made. But it would seem that nobody wanted to make those definitions. The document was eventually published by HGC – as the original consultation document and with no amendments or clarification of definitions. Everybody was happy to state the shortcomings of the document, but nobody wanted the auditable evidence trail to lead to them if there were problems with any new definitions. Nobody it seems wanted to 'grasp the nettle' and make the much needed updates to the definitions – definitions which may well affect the very future of Homo Sapiens. If those groups set up to discuss and define the issues are unable or unwilling to do so, how can there ever be an educated debate from which genuine informed consent can flow?

The announcement of a National Screening Programme for the Haemoglobinopathies was also intimated at the January meeting[148], and was more fully discussed at the meeting held in February 2001.[149] This announcement was foreshadowed in the government's NHS Plan in July 2000, in the section entitled 'Children: Ensuring a Healthy Start in Life'. Somewhat ironic as the only cure for thalassaemia, and, I believe sickle-cell, is the termination of the foetus. The programme was to screen for these two 'diseases', '…both of which were conditions predominantly affecting non-Northern European people…'[150] I am aware that this quote refers to ethnic origin rather than place of birth. However, it speaks most cogently of how the state views 'South Asians' and 'Africans' as 'the other', outwith the UK 'white' population. The minutes pay lip-service to '…specific sensitivities about

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[146] http://www.hgc.gov.uk/subgroups/genetic_testing_12january.htm 6.1
[147] http://www.hgc.gov.uk/subgroups/genetic_testing_03december.htm 8.1
[148] http://www.hgc.gov.uk/subgroups/genetic_testing_12january.htm 6.2
[149] http://www.hgc.gov.uk/subgroups/genetic_testing_16february.htm 3.1, 2,3,4 & 5
[150] http://www.hgc.gov.uk/subgroups/genetic_testing_16february.htm 3.1

race...'[151] and issues of programme implementation. There is some discussion of '...obtaining properly informed consent...'[152] and the need to consider the '...various communities...' within the minutes.[153] Also, Professor Anionwu pointed out the difficulties of attempting to identify those to be screened by ethnicity as such attempts have in the past caused offence and also suggest that this method supported the misconception that these conditions only affect black people. I return to these issues later in this part of the thesis. However, at this point I will comment on how I see these issues impacting on perceptions of risk, in this case genetic risk. Although Professor Anionwu is aware of the need to address these issues with sensitivity, she is perceiving risk from her medical perspective, not from the perspective held by the majority of people for whom this is an important personal issue.

In all of the above I suggest that there is prima-facie evidence of the professionalisation culture that pervades every walk of life in Britain today. Everybody wants to produce an auditable evidence trail, but nobody wants to make an attributable decision, which may, at some future time, lead to litigation or become in some way problematic. Essentially the HGC followed the lead, concerning the definition of serious handicap, from ACGT, who in turn adopted it from the RCOG, who in turn had adopted the United Nations definition from the late nineteen-forties. All parties criticise the UN definition (c1947), all decline to make a 'better' definition. So if such an illustrious group will not make decisions and 'work outside the box' to benefit their fellow man [sic] why should we look for different attitudes from those lower in the food chain? I suggest this is a case of leadership by example. I do not think it too strong a criticism when I suggest the NHS could be described as 'lion[esse]s led by donkeys'.

Some stories from the classroom:

There is an increasing fear of litigation within the Health Professional's side community (cf. Douglas 1986, 61) which makes a traditionally individualistic group conform. Audit at once frees and binds the individuals within this group. However, Douglas

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[151] http://www.hgc.gov.uk/subgroups/genetic_testing_16february.htm 3.2
[152] http://www.hgc.gov.uk/subgroups/genetic_testing_16february.htm 3.3
[153] http://www.hgc.gov.uk/subgroups/genetic_testing_16february.htm 3.3

(1986, 61) suggests that mutual shielding by Health Professionals in Britain leads to more professional boldness. She suggests that this system protects the decision makers from blame (Douglas 1986, 61). I argue that one of the purposes of audit is to ensure that blame cannot often be apportioned to an identifiable individual or organisation.

This attitude is taught in medical school and is normal in the work groups I have talked with. I give some examples here. I asked a male third year medical student if he could envisage advising a patient of a course of action, if asked. He replied *'I hope not!'* He said he would give the patient all of the information and then let them make the decision. I then asked if he thought that was fair, for he, not the patient, was the one with the education, training and experience. I said that I was aware of the claims of potential litigation, but did he not think that audit culture had gone too far in this respect. I suggested that his argument, although in his best interests as no blame could be attached to him, was not in the best interests of his patients. After all he had the training and knowledge to make a truly informed decision – while few, if any, of his patients would ever be in that position. He reluctantly agreed that my argument was valid but said he would continue in using current practice [auditable evidence trails, guidelines, protocols and procedures] as outlined by the NHS. If he did not then he would lose the support of the NHS in the event of litigation. The enculturation process is clearly evident here.

A third year female medical student told me how she would tackle the increasing ethical minefield thrown up by genetics, creating new dilemmas almost daily. She was particularly concerned about when genetic 'cures' came online. If chemicals were problematic [thalidomide] then how much more so would be therapies that altered the very essence of life [DNA] and could affect future generations. She said:

> 'I think it is very hard when you come to the ethics and morals in medicine…it's hard, especially when the NHS has a particular policy and it has a particular view on the particular situation which you might find… unethical… probably at the end of the day. I'll just have… follow through with NHS policy… if it ever came

to the crunch whereby if I did this particular thing because it's how I felt ethically but it would get me suspended or even lose my licence to practise then maybe then I would have to go against my own ethical beliefs and follow [NHS protocols] ...'

This puts one in mind of the Milgram experiments[154] (Tassano 1995, 62-3). It raises serious concerns when a young woman in the third year of her training is so worried about litigation and sanctions she is prepared to go against her principles and behave in a manner she feels is unethical. Another third year medical student told me her thoughts on possible litigation if she directs a patient towards one form of action over another:

'...that's why... doctors are now not just saying "I think you should go for this option"... now they just give the statistics – this has been the case for the last ten years... the alternative is to possibly risk litigation...'

Clearly there has been much time taken in the teaching of these ethical dilemmas and also much thought given by the students. You can say that they enter the world of medicine prepared for the modern world, or that they are programmed to act in uncharacteristic ways before they even see their first patient. How you view this is a matter of perspective in the end. But it clearly has implications for what is said, and more importantly how it is said, to patients and the increasing difficulties faced by the lay population who interface with this new breed of physician.

Some stories from the consulting-room:

I asked similar questions of GSMs and midwives on how they deal with giving information to patients and with patient requests for specific advice on one action over another. Did they not feel that they were transferring responsibility from the Health Professional [where it belonged as the 'expert'] to the patient [the medically uneducated]? I was told by one GSM:

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[154] The Milgram experiment was a infamous social psychology study. It was intended to measure the willingness of a participant to obey an authority who instructs the participant to do something that may conflict with the participant's personal conscience.

'...informed consent is good to a certain extent but... you don't want to sort of overwhelm the person with information. And also if it is ... a major decision and [they] have to choose between having 'x' or 'y' procedure. The person has no previous medical background and isn't really qualified to make a decision. You know what you would do personally, but you can't tell them that. This would, to some extent, put the patient at ease cos they know that it's a decision made based on medical backgrounds not on a non-medical background. But in the end it is their decision to make; they have to live with the consequences.'

I can see that if someone is faced with a whole series of facts and little knowledge to fall back on, the simplest decision would be to trust in Allah. At least then there is some degree of 'certainty' and it is the world of the familiar. At least from Islam there is some direction offered, unlike the medical realm where actors are too afraid to become involved as sanctions will almost certainly follow.

With one GSM, Jane, our conversations would often return to aspects of professionalisation. We discussed the increasing professionalisation of society in general and then developed the theme and considered the implications for her role within the NHS. I asked how her role had changed and how change has been affected year upon year. The first area that the GSM identified was performance targets set by the state which have to be met by those working within the NHS. She told that most often change was implemented via new guidelines or protocols which are issued every time some 'error' is exposed. McPherson[155] and Alexander[156] resulted in more pages being added to the manuals and further changes in procedure to tackle institutional racism. Jane felt that if there were problems they should be addressed. However, the most common response was 'knee-jerk' reaction which led to new protocols being instigated from above. Measures that often had an effect that was counter to that envisaged by the planners. Something of a 'bow-wave' of institutional racism, I suggest.

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[155] Author of the Lawrence Inquiry, whose definition of institutional racism is often cited. See also footnote below.
[156] Author of the report on institutional racism with the NHS.

Many of these Health Professionals I spoke with felt that most of their work was involved in meeting some sort of political agenda and not directly related to what they perceived as patient care. This was particularly strongly felt by the midwives who had to deal with such change on what they sometimes felt was on a day to day basis. There was a constant need to check new protocols.

The Politicisation of Culture:

Culture, like audit, has been usurped by the New Right (often known as Thatcherism in the UK) and remodelled to fit their soon-to-be-dominant ideology. As Bourdieu (1991) describes it, politicians and decision makers have introduced culture into their discourse in many different fields. The New Right used their power to project negative meanings of key symbols and terms, for example regarding minority ethnic groups. At its height New Right Ideology appeared hegemonic. Many legitimate minority groups in the UK were, as Wright puts it:

> '...marginalised, excluded from their [New Right] dominant notion of 'Britishness' and demonised as a danger to order and subversive to the state.'
>
> (Wright 1998, 5)

As Wright notes, the reformulation of nation in terms of culture rather than race attempted to define racism out of existence. Minority groups had a choice of assimilation or repatriation – a very similar choice to that offered to the Jews by the Nazi Party. Many of my informants fear this may still be the case today – '...just look at Yugoslavia...', one said to me.

I would agree with Asad (1979) that culture does not mean a set of ideas and meanings shared by a whole population of homogeneous individuals. Sadly the NHS, and the British state which controls it, do not seem to have grasped that. Based upon empirical evidence, this is the case for South Asians or for that matter 'ethnic minorities' as a whole. The very term 'ethnic minority' carries at once within it a sense of homogeneity and a sense of 'other' – and a subordinate 'other' at that. For me a better way to locate the majority of those members of minority ethnic groups, in Britain, would be Hall's idea of them having

'…dislocated histories and hybrid ethnicities…'(Hall 1993, 356). Also applicable is Wright's notion of '…cultural identities… [that are] not inherent, bounded or static; they are dynamic, fluid and constructed situationally, in particular places and times' (Wright 1998, 4). Hall and Wright describe very well the processes and unequal power relations that I have encountered and which have been recounted to me over the period of my fieldwork in both Britain and Pakistan.

But all sides can invoke culture as a political trope. Wright (1998) described how the Kayapo (South America) used their 'culture' to gain funding and in some way redress the unequal relationships they have with the ethnic majority. Similarly the same has been accomplished by the minority ethnic groups in the UK. However, they have not been as successful in playing the 'culture card' – more often called the 'race card' in Britain. Also 'playing the race card' can rebound negatively. Minority ethnic groups are given their 'wedge' of the funding, for example the Standaira project in North Shore, and are then dismissed from thought. The 'ethnic box' had been ticked – criteria-met funding has been delivered. One of the reasons for a failure of ethnic minorities in Britain to assimilate may be that funding for 'ethnic diversity' has been lucrative and many gatekeepers have found gainful employment in the 'industry'. Thus in the early phase of the South Asian diaspora assimilation was as complete as was possible within the constraints of British culture and the economic milieu in which the men found themselves. Then came the Thatcher Revolution of the 1980's with concomitant economic retrenchment driving the often unskilled workers into either unemployment or self employment. The increase in racism in the general population, and by the state, drove many ethnic Pakistanis inward upon themselves. This insularity was fostered by the need for ethnic Pakistanis to exhibit their 'culture' to gain funding for their 'community' within the wider social context – it was the world of grants and matched-funding. The 'Braxton-Hixs'[157] of audit were beginning.

For example, Riverside council had to bid for the Single Regeneration Budget (SRB) funding, a project that is said to have stemmed from Premier Thatcher's *Walk in the*

[157] Practice contractions, in preparation for the actual contraction of birth.

Wilderness[158] in 1987. Any such bid had to meet the criteria set by the Government. It would also have to be audited and have achievable outcomes. Audit culture was central to the SRB. Thus what the people wanted and what the council had put in the bid proposal were often at odds. The fault lay with audit culture and not with a deliberate act by an uncaring local authority, which was how many people from North Shore felt about it. Thus we see that out of good intentions from individuals the very act of trying to make things better results in either indifference or a perceived worsening of people's daily lives. Examples of this can be seen in two cultural events in Riverside.

One such cultural event which was intended to promote multi-culturalism and develop understanding among the diverse communities, was the annual *Mela*[159] held in the Victoria Park. This event was open to all Riversiders, although the few 'white' faces there were middle class types. I met many people I had already interviewed and several new acquaintances that day. The event was planned to celebrate South Asian culture in Riverside. It has been said to me that it is '…when South Asians let their hair down…' And in many cases quite literally, for most of the young women there were either in western dress (though modest) or *shalwar-qamis* or *saris*. All had their hair loose. One young man I met (a student that I taught at the college the previous year) said the women were '…dressed to kill…' He felt that the *Mela* was the only opportunity for Asian [but he meant Pakistani/Muslim] women in Riverside to relax and be seen by prospective husbands. He told me that many marriages would be arranged as a result of people [girls] being seen at the *Mela*. The brothers and fathers and uncles would be too busy to watch them [the girls], as they were too busy '…eyeing up all the talent…' I asked Abdullah about this later and he said, somewhat wistfully, that Islam was a good religion that allowed for people [men] to be human. He said that it was 'OK to look [at women], but only once. After that it was a sin…'

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[158] It was allegedly that walk in the Thornaby district of Middlesbrough that persuaded Thatcher that something must be done about Britain's decaying inner-cities. Yet that urban wasteland would probably not have been there to begin with were it not for the wholesale destruction of manufacturing industry that occurred in the first two years of Thatcher's reign. The North-East lost 40% of its manufacturing jobs virtually overnight as the cold blast of monetarist theory laid waste the region's economy.

[159] A fair or Hindu festival, somewhat ironic choice of title as the majority in attendance were Muslims.

I commented on the quality of food at the event to Abdullah, one of my friends from North Shore. He said he would not eat until he got home. He went on to explain that no Asian would be eating there, unless they had brought their own food. The people who had the food stalls were only out to make money and furthermore they were bad cooks and dirty – '…you'd get food poisoning from eating….', he said. Then he laughed when I told him I had already eaten: '…serve you right Richard, you should come my house to eat ...' In reality the event was a day out for the ethnic Pakistanis with the odd 'outsider'.

Another 'multi-cultural' event that I attended was the 'Home Stories' event at the Standaira Centre, the minority ethnic community centre in North Shore. A white author, from Bradford, was collecting stories of South Asian women's recollections of home (Pakistan, India, Bangladesh) and also memories of their journeys to and experiences of arrival in the UK. When I arrived there were about fifteen to twenty women sitting around on chairs arranged in a half-circle with a table and three chairs at the front. On the chairs sat Shafiul Karim (Centre Manager), the author and Ruby (one of the then Standaira community workers). There was also a laptop (the Standaira's I assume) in front of Shafiul. There were also two men in the audience. I chose a chair at the back, on the left so as to be able to see everyone in the meeting. Again, we shall see that the official cultural intentions behind the event were not found meaningful by the ordinary folk who attended.

Shafiul had invited me as she thought it might be useful for me to hear the stories of the women and get some sense of how their experiences impacted on their lives today. Before the meeting started Shafiul told me that she would be taking notes of the event and I could have a copy, '…so no need to take any notes or use your tape recorder…' I was never to get the transcript of this event. As events unfolded that day little did I know of their far reaching impact on my future research opportunities in North Shore. It turned out that the most interesting observations, that day, were things that did *not* happen and things that were *not* said. Thus Shafiul's choosing to 'cut me out of the loop' that day and the reasons for her

removal of her 'patronage' arose when she became aware that she was unable to control my access to *her* community.

The whole event was about power and control in every sense. One of the problems for the NHS, or any organisation, in accessing what they believe to be 'minority ethnic communities', I argue, is that often such access is controlled by gatekeepers. In the case of ethnic Pakistanis in North Shore the council, the state, the NHS and education providers all channelled their input via the Standaira Centre, or rather, at this time through Shafiul Karim, the manager. The Home Stories event was no less controlled, by Shafiul, and was fecund with power relationships, both explicit and implicit. The author was in the hands of the Centre, as he needed to access the 'community' to write his book. The women were there because Shafiul had told them to be there. The Centre staff, under Shafiul, had to act out their roles – in an audit culture the yearly appraisal was used as a measure of your performance. The food provided after the event was paid for from the Centre funds, and cooked by the Deputy Manager Yasmeen's mother. I was there, so Shafiul believed, under her patronage. The two men were there to see what was going on and, I have no doubt, report back via gossip to the other men.

The author spoke to the group, but his approach was too loud and intimidated the women in the room. He had said that he had many years of experience with the 'Pakistani communities' in Bradford and elsewhere – he had '…many Asians friends…' My take was that that was not entirely the case; otherwise his approach would have been more circumspect. One sign of his ineptitude was that he did not allow the women to tell their stories, in their own time. Shafiul also interceded, almost constantly, and told the women's stories for them. Ruby 'translated' the author's words into Urdu. As I had met, and interviewed, the majority of the women in the room I knew from personal experience that they did not need the translation, but it was given as an example of the power relationships within this setting. I made little of the stories, for there was little told. The author seemed

happy with his trawl, filtered through Shafiul. There was a break for tea about half way through the morning.

Yasmeen (an ethnic Bangladeshi) had left the group to make the tea and bring forth the biscuits. When the meeting broke I went over and asked if I could do anything – I carried in some plates of biscuits – and also asked Yasmeen how her wrist was. Last time I had been at the Centre her wrist had been in a plaster cast, as she had sprained it. Yasmeen seemed to be both surprised and happy that I had remembered her injury. We rejoined the group. Many of the women came up to me and began to chat about their lives and my fieldwork. After about ten minutes Shafiul approached me and said '…I was going to introduce the women to you, *but I see that you already know them*…' From her tone and body language it was clear that she had planned to introduce me to selected women and maintain her role as gatekeeper, offering to arrange meetings and carry out translation.

I told her that Salina had been introducing me for some months and that I had met and interviewed most of the women in the room at least once, and several of them on more than one occasion. Shafiul then reconvened the meeting and we all sat back down. That was the last time that I was invited to a Standaira event. Shortly after this event I tendered for some research looking at minority ethnic access to health for Standaira. I did not even get short-listed. The successful applicant was my then co-supervisor… who claimed that she did not know I had an interest in the project. Shafiul later left the Centre and there were no more events there; the Centre had begun to wane. My last information was that the funding would expire in November 2003, and the general consensus was that it would not be renewed. I also heard that the building was to be demolished and that plans had been passed for the site to be redeveloped for housing. So, the 'Home Stories' event was my last formal visit to the Centre.

After the tea-break the women began to leave the room in ones, twos and threes over the next hour. Shafiul told me that they all had to leave to get their husband's meals ready. My take, confirmed with some of the women in conversations later, was that they had

'shown the flag' and, duty done, they returned to their own lives. Most of the women, and all of the men, were very quiet, and only those asked specific questions, mainly by Shafiul, made any contribution. Most of the stories were told by Shafiul on the women's behalf. This reflects much of what I observed with regard to the interaction of the state and the minority ethnic Pakistani side in North Shore.

At the end of the meeting there were perhaps four or five women who remained. Four women and one man arrived and were introduced to me as community workers from Cattleville. They thanked Shafiul for inviting them to lunch, to which Shafiul bade them: 'Be quiet!' The women from North Shore said their farewells and left. When it was certain all of the women and men from North Shore had left the food, sufficient for a medium sized banquet, was produced from the kitchen area. We began to eat and chat about our respective work and what issues had arisen from the 'Home Stories' that had been related by the women. I kept my thoughts about the event to myself and continued to observe the interactions of this group. It was clear that two of the workers from Cattleville were Indian, and that they (and I think Shafiul from her demeanour) thought themselves superior.

Two related incidents occurred with the banquet. The first was that Shafiul commented on how full my plate was. I replied that I had been told by several ethnic Pakistani men that I '…eat like a woman…', so not to offend anyone I was eating lots of food, very quickly. The second thing that occurred was that as soon as all of the people had filled their plates Shafiul, Ruby and Yasmeen began to remove the platters from the table and return them to the kitchen - thus giving no chance for anyone to return for second helpings. I asked Yasmeen what was to happen to the food that was not consumed; she said that '…the centre staff would take it home for their teas...'. So not only did the Centre's funders pay for the food (prepared by Yasmeen's mother), they also fed the three workers and their families. As I have said, there was enough for a medium sized South Asian banquet, and most of it was taken home for their families. From talking to people in North Shore I got the very strong sense that the whole project was run for one family, the Karim's,

and that the other Centre staff got the crumbs, to keep them quiet. Shafiul's father 'Old Karim' had just recently died and Shafiul saw herself, according to Salina and others, as being his rightful heir as the 'community leader' and 'spokesperson'.

Initiatives:

The Standaira Centre in North Shore, is perhaps the most graphic example of an externally funded initiative in Riverside. Local FE colleges and the WEA[160] fund the Centre. The idea of a 'separate community centre for the Asian community' of Ironopolis had been discussed in the past and the Asian Survey (CCRI 1982a, 15) provided an opportunity to test the level of interest in the idea among the Asian population themselves. Of the total 438 respondents in the survey '44% (193) were in favour of a separate Asian community centre, 46% (200) were not in favour' and the remaining 10% (44) were not sure one way or the other (CCRI: 1982, 15). There was little difference in terms of respondents' country of birth or age with regard to support for a separate centre. The survey reported that women were slightly more likely to want a separate centre as they were people who spoke little or no English, so they were less able to mix outside a limited network. Also the survey reported that Muslim men had not made provision for women to pray at the mosque. As the Qur'an gives women dispensation to pray at home this is often taken to mean women *must* pray at home – the mosque is male only. So we have more than half of the Pakistani population of Riverside who did not specifically want a separate community centre – outside the home they would rather continue to make use of facilities available to the general population of Riverside.

Despite this lack of an overwhelming need, the Standaira Centre was funded and it opened in the late 80s. The Standaira Centre stands on the very outskirts of North Shore, surrounded on three sides by wasteland. There was a two metre high fence complete with both razor wire and rotating spikes surrounding the building. Every window has bars and/or heavy mesh shutters. The entrance doors are clad in metal and there is no letterbox - to prevent arson attempts - all in all, a bleak building, in a bleak location. The main aims of the

[160] Worker's Education Association.

project were to develop employment opportunities and act as a springboard into Further Education for the North Shore minority ethnic [Pakistani] groups. Also the Centre was to help unemployed South Asians get work or train for work. More generally it aimed to help to develop the 'Asian community' in North Shore. New Money, from the European Union, the Single Regeneration Budget (SRB) funding for the project was certainly going to make the Centre 'bigger and better' in the next few months, I was told when I started my research. Full-time workers were to be appointed in the near future, (hopefully from the local community), the SRB community newspaper heralded. This did occur: the manager was from the majority 'Pakistani community' and the deputy was from the minority 'Bangladeshi community' in the town. The managers and other employees were ultimately answerable to the 'white bosses' of Riverside Council.

When I went to the Centre, Shafiul, the Centre manager, outlined several projects the Centre had been involved with. One was helping unemployed members of the ethnic minorities in Riverside to find employment. I witnessed this in action. A male ethnic Pakistani (late teens or early twenties) was in the process of apparently being 'helped' to get a job. The encounter seemed fraught with tension. The man made a point of getting the name and phone number of the person to whom Shafiul had spoken to. The reasons why he was so insistent may only be guessed at. Did he did not trust Shafiul? So he could phone them and cancel the meeting? So he would be able to contact the employer or prospective employer in future directly? Or simply just in case he got lost or was going to be late for the interview? I also did not fully understand Shafiul's equal resistance to providing the man the information. As I read my notes, to write up, it put me in mind of the power and control issues that I myself had experienced with Shafiul. Also, other notes in my diaries suggest that these issues had not gone unnoticed both by the Manager of the Women's Centre[161] and by Salina (the line manager for both the Centres at that time). Both women had commented to me that I should 'watch my back' around Shafiul.

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[161] North Shore also had a council funded Women's Centre, built in the centre of the town – open to all women, and very well used by the ethnic Pakistani women for courses and socialising with other North Shore women, of all nationalities.

The Standaira Centre was supposed to '...strengthen the ethnic community...', according to the article in the *Way Forward*, the community magazine of the North Shore Community Forum. Thus one example of an event organised by the Standaira Centre Manager, for the 'ethnic minority communities' in North Shore was 'Multi-culturalism on Tour'. The following events were staged by the Standaira Centre between 18th April 2000 and 29th April 2000 (one should bear in mind that the majority of the minority ethnic groups in North Shore are Muslim): a Salsa Band, a showing of Disney's *Mulan*, a group of Gospel Singers, a Samba Workshop and the *Funjabis* (South Asian slapstick comedy group). Some events were held in the Standaira Centre itself - other events were held in either the Women's Centre or the Baptist Church. As might have been guessed, most (if not all) of the events were not suitable for ethnic Pakistanis and for the same reasons most of the events were unsuitable for many members of the other ethnic groups in North Shore, as the majority were also Muslim. Furthermore, most (if not all) of the women did not attend any of the 'suitable' events, because Shafiul had alienated most of the minority ethic population of Riverside by that stage, I had been reliably informed.

The Standaira Centre focused on ethnic Pakistanis, rightly or wrongly, but consistently failed to meet the needs of that, or any other, group in North Shore – from the evidence of my informants. My interpretation is that thus it was just another piece of 'audit' performed to meet a set of outcomes and targets stipulated by SRB funding criteria. These initiatives were seen by many residents as just another 'bad joke' from Thatcher's 'Walk in the Wilderness', in 1987 – about which the majority of the population of Riverside are still not laughing.

When I returned to Riverside in 2003, Tazneem, a local informant, told me that she had little contact with the community development workers who worked at the Standaira Centre, nor had anyone else in Riverside. Standaira Centre had '...gone right down hill...' since Salina had left the project. I said that I had heard that this was the case from others in North Shore. I said I had been around to the Centre to see what had been happening since

my last visit, but the door was locked and nobody answered my knocks. Tazneem laughed and said '...ah ha...' and then added that Yasmeen, the acting Centre Manager, should have been there – then as an aside said, 'Perhaps she was on her lunch...' However, as the conversation progressed it transpired that Yasmeen's absence from the Centre was not unlooked for. It was suggested that as Yasmeen was a somewhat passive individual her ('white') bosses had largely been able to ignore the project and for that matter Yasmeen – but the 'minority' box had been ticked. Tazneem continued by telling me that there remained a rift between members of the minority ethnic population and the Centre workers. Yet, this rift was, according to Tazneem, largely ignored by the council although she had little doubt that they were aware of the situation. The money had been spent on the 'ethnic minority' project, and to meet audit criteria, support was no longer necessary. The audit culture juggernaut had moved on to pastures new, leaving the minority ethnic population in North Shore to sink back into isolation.

In Scotland also there were instances of this audit culture performance to meet 'ethnic need'. Again this need was apparently some way behind actual need and, arguably, largely constructed to meet a supposed need. The Islamic scholar[162] at one of the larger mosques in Scotland told me how the mosque had been visited by a delegation from the Area Health Board. He told me there was a meeting held at the mosque where the representatives of the Health Board asked the men a series of questions. The scholar reported that their questions were '...regarding... their [the Muslims/Pakistanis] treatment. How do we [the Muslims] see their [NHS] treatment towards the Muslim patients? ...' He continued to narrate the events he had participated in. 'A few Muslim brothers took part... (Note: Men only gave their views to the Health Board at this meeting) Each and every one gave their views. For example, regarding waiting lists, waiting times, how the doctors have responded to specific needs like tropical diseases as some brothers come from the African continent. The concern was that some doctors may be oblivious to or know little of such

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[162] Many larger, wealthier, mosques have scholars – *hafiz* - who answer questions on the Qur'an, Hadith and Shari'a law. They are experts on Islam.

tropical diseases…'. 'He felt that the meeting was very beneficial as they were also '…informed about the complaints procedures…' So no particularly 'ethnic' issues were broached by either side, particularly in the areas of thalassaemia or sickle-cell.

The scholar continued by telling me that there had also been questions specific to Islamic health needs. Vaccination in preparation for *hajj* was mentioned when '…one Muslim brother said that when he went to his GP he found that neither he nor his GP knew the correct vaccinations needed for a trip to Saudi Arabia. Furthermore, the vaccination, when identified, was not available without charge. One of the biggest complaints raised with the health board delegation was about the lack of adequate signposts directing Muslims to the prayer hall at Integerpool Hospital. Furthermore, the return journey from the hall was also problematic and '…took the Muslim brothers about twenty minutes to find their way back as they kept getting lost.'

Again nothing particularly challenging – a MASTA[163] leaflet could be acquired from any chemist, travel agent or GP surgery. One would imagine that signposts were quite far down the agenda for an overstretched NHS, there were perhaps more pressing health issues to discuss such as the NSPFTH or screening programmes or specific moral and ethical issues pertinent to Islam. As most of these men have lived in the UK for more than thirty years or were born here one would think the points were fairly trivial in nature, and much more pressing matters were left undiscussed.

I was unable to find out the names of the Health Professionals who had visited the mosque, so I was not able to get their side of the story and ask what their aims and objectives were from this encounter. However, I think it likely that they would not be too dissimilar from those found in Riverside. That is to say an attempt to make NHS services more 'user friendly' and 'patient centred' with regard to 'ethnic minority users'. I would further guess that only I would find the encounter problematic. The Health Professionals will have an auditable evidence trail offering proof that they are 'working towards' a better experience for 'ethnic minorities' in their health region. From the perspective of the men

[163] Medical Advisory Service for Travellers Abroad Ltd

they have had their say and are happy that they have been consulted on issues that concern them. However, nothing regarding the more fundamental issues seems to have been attempted by either party. Nor, and I would argue most problematic, were the women consulted. One could argue that if the major issues for minority ethnic health-care were merely poor signposting at Integerpool Hospital and GP receptionists not pointing out the MASTA leaflets to patients planning on travelling abroad, then the identified problems could be solved overnight. I argue that the Health Professionals, caught up in audit culture and trying to 'do the right thing', are unable to see the 'woods for the trees' with regard to minority ethnic health provision. This situation is clearly not helped by gatekeepers' somewhat lax attitudes towards important ethical and moral questions around current health provision. By this I mean, in this instance, the mosque committee who failed to bring more into focus pressing issues perhaps around women's health, childbirth or the NSPFTH to the attention of the health board. Instead, they appear to have used the meeting to perform cultural stereotypes of Muslims for their NHS 'audience' thus reinforcing the state's perceptions.

In Riverside I was told by one of the younger men that: '…the old men are not getting what people want out of the funding'. All that was got was a computer. That is not what is needed for the younger generation in the area. A pool table and stuff would be better… For the old men something other than film shows down the mosque…' This informant had planned to get onto the mosque committee and try to bring about changes. Although he has respect for the older men on the mosque committee, he felt that he would like to take a more active role in '…community politics'. He felt it was time for a new generation to take over and meet new challenges.

His description of his 'community' sits within what Wright (1998) has called the 'politicisation of culture'. The mosque committee looks to spend the money gained in grants wisely. However, these decisions are influenced by input from the professionalised middle class – whatever their ethnic background. The situation is one where 'working class'

committee members become enculturated into middle-class values and thus led by 'outside' middle-class input. In microcosm it mirrors what has happened with the SRB. The purchase of a computer rather than a pool-table was, for the man I spoke with, a case in point. The committee have gone for the education value of a computer rather than the entertainment value of the pool-table. Also, funding for a computer is much easier to justify on a grant proposal, even though, according to the informant, that is not '…what the kids wanted…'

I met Surraya, the manager of the Talcap Ethnic Minority Health Initiative, in Cattletown (Riverside), in 1999. We talked of the work that the project was set up to undertake. Talcap, Surraya told me, translates from Urdu literally as 'health house', but in the case of this project it is translated as 'health home' which denoted the ethos of a place that offers safety and security and friendship and support. Both of the information leaflets promoting Talcap that I was given were written in English only, suggesting, at least for the area covered by the project, English was the language to express their 'ethnic minority' mission statement in.

The project was, according to Surraya, mainly an advocate service for interactions between South Asians and Health Professionals in the hospital context, but people increasingly want the same service at the GP surgery. Even those who spoke English well (the majority from my experience) use the service for support; according to Surraya, '…it puts the doctor on his or her best behaviour…' In the light of this suggestion, without the Talcap intervention doctors may not be on their '…best behaviour…' I began to discuss with Surraya what I had been told by Raj Bhopal, an epidemiologist, about his work in Riverside, when we had met at a conference the previous year. He, along with Surraya and Madhok (Madhok et al 1998), had recently conducted a survey of ethnic minority women's satisfaction with treatment, as inpatients, at a Riverside hospital. The finding suggested that women had few, if any, problems accessing health care in Riverside.

I suggested that Bhopal's findings were flawed. For instance, there had been no account taken of the cultural aspects, noted above, regarding women from the ethnic

Pakistani side – most noteworthy would be answering polite questions positively. I had not been able to access the article on which he based his assertions, although I had checked the journal that Bhopal had claimed would publish it diligently since the conference. Surraya was co-author of the article (Madhok et al 1998) and was able to supply me with a copy. Many of my concerns with Bhopal's analysis given at the conference had in the event been addressed in the article. I seemed to have been correct in my first analysis; there were problems with South Asian access to health care in Riverside. One of the strongest proofs, apart from the word of my informants, was that Surraya had a job managing the Talcap project. Although Surraya argued that Bhopal was right in his final analysis, she also agreed there was evidence for my argument that communication, not language, was problematic between these two sides.

There have been several other 'Asian Health Initiatives', both UK wide and local endeavours by Health Boards and councils. They range from the national *Asian Mother and Baby Campaign* initiative of the early 80s to various local health initiatives to modify the diets of Pakistanis, with courses encouraging women to 'cook without ghee' in an attempt to cut coronary heart disease in Riverside (to take an example). There were also health education initiatives (heart disease, healthy cooking and eating) that had been offered over the past couple of years. Most of the women I talked to felt that these initiatives, which they often thought to be paternalistic or patronising, had a very limited effect on their lives or those of their families. Some informants viewed these initiatives as attempts at social policing of certain members of the population by those who thought they were their social betters – 'The Asian Mother and Baby Campaign' being a prime example of this.

With regards to very many initiatives, I have made notes postulating that middle-class South Asians seemed to have a vested interest in defending the status quo and preventing outside access their local area. I have not had problems with accessing working-class Pakistanis either in England or Scotland over the whole time of his research (with the exception of 9/11 linked stuff). Yet the same issues of '…Islam forbids…' or '…it's a

sin…' crop up every time I talked to 'Western', 'modern', 'educated', 'professional' ethnic Pakistanis. The most likely explanation for this positioning was what I call 'gatekeeper' mentality. They claimed to speak for 'their community' [South Asians] but did not *know* the realms that most of their fellows occupied or their culture. Their cultural knowledge is from their 'elders' – very often semi-educated men who believe that their conflation of rural tradition and religion is a true interpretation of Islam. These gatekeepers rarely meet any 'white' person who has taken the time to research and discuss the realities. The shorthand coded description of 'their community' is sufficient to get funding allocations granted. I suggest that these people had become what a young Muslim woman had called 'Muslims by name, not Muslims by claim'. That is, they called themselves Muslim, but had no real understanding of Islam, just traditional cultural stereotyped views which they claimed as religion, in a manner very similar to what many young women have accused some ethnic Pakistani men of doing to maintain dominance over their wives and daughters. An alternative explanation for gatekeeper positioning is they capitalise on their awareness that there is a knowledge gap between how the ethnic majority see the minority ethnic groupings in the UK and the reality. The gatekeepers cynically keep the reality hidden from the outside, to keep themselves in employment (much like the 'bladders' in *Gulliver's Travels*). A final option I had noted down was that the gatekeepers genuinely believe that their understandings of the local 'communities' were accurate. They saw people with problems almost on a daily basis, they only discussed these problems with their fellow professionals. So in their realm the stereotype that local people are beset with problems that they cannot resolve themselves was accurate. I could not say with any certainty which of the three options was closest to the truth. However, my suspicion is that it is a complex mix of all three. There is clearly self-interest at work, but I suggest that the main motor for this stance, for most, is a genuine desire to help their fellows.

Institutional Racism:

What do I mean by institutional racism? Why is it important to my argument? I have said earlier in the thesis that I have used McPherson's (1999) definition (see page 27) essentially because Alexander (1999) has quoted it and everybody accepts it to be given – a baseline or a benchmark – note the 'audit-speak' in these terms.

McPherson is somewhat unique in the realm of audit – he makes a bold, original and attributable statement. This is very unusual and almost unique within the culture. I have previously criticised the HGC for not daring to give a more current and accurate definition of *disability* rather than relying on one made over half a century ago by the United Nations. Now, relying on McPherson, I appear to be taking the same easy option regarding my understanding of one of the central tenets of my thesis. Am I being mealy mouthed here? My answer is a quite unequivocal *No.* My reason for using McPherson is simple; I see no need to reinvent the wheel in this matter. To paraphrase Bhopal (1998a): '…I think we know enough…'

Also, my argument travels the same pathway that McPherson and Alexander have opened up. My intention is to open the path a little more in the hope that my informant's voices may reach the ears of the policy makers. In short, I want to make a contribution to the debate. My first criticism of McPherson is that his attempt to move towards a solution to the thorny issue of institutional racism has itself added to the problem. He has provided a benchmark for organisations to measure their efforts against. His definition has become 'set in stone' – enshrined by the very culture he was speaking against. Organisations and the state have bent over backwards to provide appropriate services to the disadvantaged groups. He refers to the '…collective failure…' of these organisations in not providing these services '…because of their colour, culture or ethnic origin…' He must have known – his whole argument centred on the problems inherent in organisation culture – that his report would instigate knee-jerk responses from the government and the large, often state owned, organisations.

The criteria named for action were colour, culture and ethnic origin. He said there should be 'appropriate' services. The outcome here is guidelines and protocols which rigidly bind workers, in this case the NHS, to react in a special and non-racist manner to individuals because of skin pigmentation. The majority of members of the major minority ethnic (not as McPherson suggests ethnic minority) were born and educated in the UK. The Pakistani population that I have worked with are a prime example of this. I have been told time after time that they feel insulted by being offered an interpreter, or feel that they are being treated like simpletons. I have been told by NHS employees that they are forced to treat people in a different way because of the pigmentation of their skin – if they do not, then sanctions will result. These Health Professionals are forced (I use this word here because it is the word my informants used) to show prejudice and ignorance and appear to be thoughtless by following the processes and exhibiting attitudes which disadvantage the very people that McPherson[164] and Alexander sought to free. In short the medium is the message – and the people I have worked with have heard it all too loudly and all too clearly.

I would agree with McPherson that '…Without recognition and action to eliminate such racism it can prevail as part of the ethos or culture of the organisation. *It is a corrosive disease'* (my emphasis). However, his definition (see page 27), taken out of context by many with the ability to orchestrate change, has, I argue, done more harm than good. The only communication that has taken place is tokenistic consultation via gatekeepers who themselves are very often either following their own agenda or are so far out of touch with their constituents' daily lives that their input is of little value to policy makers who wish to follow the spirit, not the letter of McPherson and Alexander. I argue that the most pernicious of these misrepresentations and thus a most significant issue is what I have called the language myth. It is to this that I now turn my attention.

Language – the *official* version:

Shaw's (1989) *Getting By in Hindi and Urdu*, is used, I guess, by everyone who attempts to access the South Asian minorities in the UK (or in the sending community) one

[164] The italicised words are taken from McPherson.

supposes. In a very short chapter Shaw tells the user about the South Asian use of non-western medical systems and the variety of these medical systems. Also we are informed how cultural context is important in making a medical diagnosis. For example, South Asians tend to express emotional distress by speaking of physical symptoms (Shaw 1989, 58-9; cf. Shaw 2000). I think Shaw is suggesting that just speaking the language is not going to allow effective communication with this sector of the UK population. The text (and accompanying audiotapes) allows the learner to attempt basic communication with members of the 'South Asian community'. My guess is if someone made an attempt to learn the language the South Asian would be impressed by the attempt, if not the quality, of communication. And importantly, they would tend to be less shy in speaking English in future communications. I certainly found this text to be invaluable in that context. I would doubt if anyone could actually carry out either a medical diagnosis or academic research on the strength of this text. I have only ever found one other language course that attempts to teach Panjabi[165] and this was aimed more at 'native speakers' or those teaching language for examination which required the user to learn to write the language also. My argument is that language problems are constructed and most [all] ethnic Pakistanis in Britain are quite able to communicate and express themselves in English. However, this view is not agreed by all.

Nazroo (1997) says that there is a need to have wider use of translators for ethnic minority consultations in Britain (Nazroo 1997, Ch. 6). My argument is that this is counter productive – in the main they can speak English, but sometimes choose, for what ever reason (racism/shyness/expectation) not to. Perhaps if the NHS was more user friendly people would feel safe and thus communicate more freely. Fear of the 'other' and cultural stereotyping exists on both sides. But more important is the need to comply with a blind adherence to government set protocols within the NHS. I discuss my alternate view in the final part of this thesis – here I give the official version of communication issues.

Alexander (1999), in her investigation focusing on institutional racism in the NHS, conducted at the behest of the Department of Health, tells us that research produced by the

[165] Bhardwaj, M R (1995) Colloquial Panjabi: A complete language course (London: Routledge)

Health Education Authority reveals that English is not the main language of communication for the majority of Asians in Britain. Only a third of Indians (32%), a quarter of Pakistanis (24%) and one in ten of Bangladeshis (10%) regard English as their main spoken language. There is some variation by age and gender. Amongst women aged over 30 years, 18% of Indians say English is their preferred spoken language, for Pakistanis it is 3% and for Bangladeshi women 1% (Alexander 1999, 24).

Alexander (1999) also tells us that in Nottingham it was found that people from Pakistan (I am not sure whether this is literal or whether Alexander is talking about ethnic Pakistanis in the UK) had particular problems, both in communicating with the pharmacist and reading labels on medicines. Many more Asian women visited the pharmacy for advice when a female counter assistant was employed who was fluent in the main community language (Alexander 1999, 31). Alexander suggests that it is the language barrier itself, which prevents accessing the pharmacist, not, for example, perhaps a lack of knowledge of the pharmacist's role. Actually, I wonder if there is a simpler answer - the women found it easier or more appropriate to talk to a female – they are after all Muslims – rather than being deterred by a language barrier. Alexander also reported that most 'Pakistanis' had high literacy levels in their own language; impressive – if true.

We are further informed that 20% of Indians, 50% of Pakistanis and 59% of Bangladeshis communicate with their GP in one or other of the Asian languages (Alexander 1999, 29-30). This reflects the fact that a very high proportion, more than four out of five Asians, attends a general practice with an Asian doctor (Health Education Authority 1999). Asian GPs comprise a large percentage of the family doctors working in single-handed practices in many deprived inner city areas. Additionally, only 1% of Pakistanis say their GP has provided an interpreter (when one was needed) and many patients had to rely on informal interpreters such as a spouse or child (Alexander 1999, 30; Green 2003, 153). Alexander (1999) indicates most initiatives to set up to tackle these issues were not too successful, because they encountered problems like time-limited funding or because the

champion of the particular initiative or project had left the organisation. Most of the report is in audit speak and offers nothing of any value to the interests of this thesis, other than to further support the contention, which I shall argue, that the state, or those it employs to inform it, have little understanding of the needs of a significant minority of the UK population.

At this point I should point out that all of the Health Professionals that I talked with knew that I was looking specifically at the relation between Health Professionals and ethnic Pakistanis in Britain. I have talked to many Health Professionals about their perceptions of the ethnic Pakistani population regarding interactions, language and communication. For example one midwife in Riverside said:

> '…they don't seem to see the importance of antenatal appointments and …they don't seem to stick to the ti[mes][166]… I've got a group of them who *don't,* they turn up when they feel like it. They don't seem to think that an appointment time's important or don't understand the importance of what we are actually doing for them… And if there's anything *wrong,* despite the fact that you might *tell* them how important it is, you know, that there is something wrong and they need to have further investigations, go to the hospital, things like that, they might not take that on-board… Errm, I know I've got a couple of ladies who haven't turned up for an appointment and I've sent them *letters*[167] out *and they just ignore it*. It may well be that they don't read English good enough to, to be able to, to understand it, but there's normally *somebody* in the household whether it be a partner or one of their other children that can actually read English adequately.'

I then pressed the midwife and asked if she felt that language was a problem in communicating with her 'ladies' who were ethnic Pakistani. The midwife answered:

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[166] This is atypical Midwives' stereotyping of Pakistani women (Ahmad et al 1991, 52, Ahmad 1994, 427 and Bowler 1993)

[167] A similar letter covering what has been said and agreed may be seen in Appendix 4.

'It depends how good you are with sign language [laughs], being able to use your hands. I think most of the time you can get most things through. It's just, you know, like at the booking in appointment and things like that where you've got a whole lot of information. I think it's difficult then. I would always have an interpreter at booking in visits so you can get everything laid out to begin with. I think when you are just seeing them for a routine antenatal you can, sort of muddle your way through really. But I think at the beginning they need an awful lot of information that you do need somebody there who can impart that information properly.'

This statement strongly suggests that there is quite a major problem with language and communication between ethnic Pakistanis and the health profession in North Shore.

Issues of timekeeping and compliance are clearly evident here, and there is also a sense that the mum-to-be is not entirely aware of what is going on or of the importance of further investigation regarding any problems with the pregnancy. But the key point for the present discussion is issues around language and communication. The midwife suggests that some one in the family will read any letters if the pregnant woman was unable to do so herself. Firstly, this makes two suppositions – that the ethical issue of patient confidentiality does not apply to ethnic Pakistanis (or any other non-English speaker) and that the woman's child, or other family member, has an understanding of the technical content of the letter (what is thalassaemia or a blood test for that matter?) and a command of language 'adequate'[168] to the task including translating the concept of thalassaemia into Punjabi?

Secondly, one thing that struck me during my fieldwork was the development of the language skills of some women. When we first met one key woman informant had on occasion to ask her husband for the English for a word when we talked. By the time of my last visit, her English was fluent. This is attributable to her two oldest children speaking

[168] A term used by a midwife in North Shore, when telling me how she communicated via letter with minority ethnic patients, to describe a level of competence in reading English.

English as their first language[169] and as a consequence the woman's English had improved greatly. I mention this as the woman had only been in the UK for a few years when we first met. Her formal education had been in Lahore, unlike the other women of childbearing age interviewed, who had all been educated in the UK. Thus, even a 'disadvantaged' (concerning language) woman that I met during my fieldwork would have no trouble in reading letters from the medical profession.[170]

Jane, GSM in Central Scotland, spoke not dissimilarly to the Riverside midwife – she said that she felt she wasted much of her time on clients when they attended the consultation but did not understand what she was saying through an inability to understand English. So far as I can tell the reason for this was that often the midwife carrying out the booking-in procedure failed to note the lack of English on the form. Significantly many of the patients identified as not speaking or understanding English turned out to be asylum seekers and the social services had not thought to provide translators or to book them via the hospital. Here there was the almost ubiquitous lumping together of virtually all 'non-white' patients into the generic category of 'Pakistani' by those Health Professionals involved in primary care.

It became clear, on further investigation, that, in line with broader patterns this thesis discloses, the problem over language lay less with ethnic Pakistanis than with Health Professionals. I often heard the surprised comment from Health Professionals that '…some of them speak quite good English…' My usual reply was that there was a very strong likelihood that *they* were probably born and educated in the UK. Often, upon reflection, the Health Professional agreed with my assessment of the situation. That said, most Health Professionals I spoke with still believed that language was perhaps the biggest barrier to achieving any form of informed consent from clients. There was also much time (and therefore money) wasted if there was a need to arrange a further appointment (with an interpreter present). This also had the effect of shortening the window of opportunity for further counselling, testing or termination of an affected foetus. This was felt to be

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[169] Both her oldest children see themselves as English, not Pakistani.
[170] I make a general assumption of basic literacy here, but note that some seven or eight million Britons are functionally illiterate – statistically some of whom must be from among ethnic Pakistanis.

especially problematic for Muslims due to religious considerations (the 120 day ensoulment issue).

Another GSM commented that language is often a problem especially if the mum-to-be has just perhaps entered the country and is not fluent in English. The GSM said often the interpretation of what she says is problematic. It may be that the interpreter is a family member, most likely the husband, who carries out the translation and thus may not either have the language and/or the education to pass on the message accurately. This presupposes that the will is there to offer an accurate and unbiased translation of the information. She told me that often she would explain something for some minutes and the interpretation would take scant seconds. Suggesting, she thought, that not all the complex information had been conveyed. Furthermore, many of the terms and concepts for genetics are conveyed in English - much of which can not be accurately translated. This often results in communication at the lowest common denominator. In addition, as the majority of Health Professionals I talked with did not speak the 'other's' language, they had no proof that their data has been accurately transmitted or that the replies they received were at all accurate. Not to mention the possibility of the family member undertaking the translation editing the flow, in either or both directions.

The issue of language and audit are well demonstrated in the Winter 2002 edition of *The Fifer*[171] in which there were two stories relating to language. The first told us that NHS Fife has joined police, ambulance and fire services in recruiting the National Interpreting Service. This service will help communication within Fife health. John Wilson, Director of Operations, told *The Fifer*: '...While we haven't had many people who are unable to speak English, this will make a massive difference for the few who can't communicate...' So we are told that there is no problem, but just in case, we have a Quango in place.

The second article, on the same page, refers to Fife's Racial Equality Strategy Group (FRAE) and celebrates the signing of the 'Racial Equality Action Plan' set up in response to a report compiled by the Scottish Executive. Again we are told by John Wilson:

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[171] A free newsletter from Fife Council and the Regional Health Authority

'...This is a very important issue for NHS Fife. We must ensure that people are not disadvantaged – because of their ethnic background or language spoken – from accessing services or being aware of what services are available to them...'

Such a highlighting of division between racial groups – fronted by gatekeeper Salma Siddique[172] – I argue perpetuates institutional racism in Britain today. This is audit culture performed in its most blatant form. Minority ethnic groups in Scotland, according to Mann (1992), have been well integrated into Scottish society for half a century or more.

Organisations like FRAE are singling out the minority ethnic groups for 'special treatment' – something the majority of people from these sides, according to those I have spoken to, do not want. 'Black and ethnic minority groups' (to be identified and segregated by skin pigmentation) who, in the words of the first article, '...have no problem...' in communicating with Health Professionals are to be monitored. Seventy percent of the population among those people were born in the UK - born British and speak and write English. Yet this Quango seeks to identify and monitor them for special treatment – against their wishes. The most frightening thing about this whole bizarre series of events is that the perpetrators perceive what they are doing as lessening institutional racism.

I have had many conversations with ethnic Pakistanis regarding language and issues around language. I said above that I planned to learn Urdu/Panjabi to carry out my research – all of the evidence said this would be essential for my research - if I could find a teacher. I had many conversations which included comments and questions around '...Why don't you learn the language?' or 'You lot [researchers] never learn the language...' My reply always remained the same 'Please teach me, I want to learn'. Always the result is the same – silence. I am fairly sure that many of the older generation in the ethnic Pakistani population are happy through being able to speak a language other than English to have their own 'secret' language that makes them special. Several times I have shocked my hosts by understanding what has been said – a conversation or comment they had thought 'private'.

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[172] A woman who commented to me, after reading a part-draft of a chapter of this thesis: 'You know more about my community than I do'.

But my never acquiring more than a smattering of the language caused me little trouble in carrying out my research in the UK. In fact, I feel it has been quite serendipitous and contributed to the overall thrust of my argument.

Institutional Racism enacted:

Kath, GSM from Jamestown, told me she thought that the culture of the Pakistani side is in some senses alien to the white Health Professional, although every effort is made to develop knowledge and take this into account when interacting with patients. She is right, for example, attitudes to abortion within the Pakistani/Muslim sides are not clearly understood. Thus time matters are not seen by the NHS as influencing factors in offering and scheduling tests. From the NHS perspective as long as it is done within the constraints set in place by the British legal system there are no perceived problems with second trimester testing - amniocentesis in particular. I concur that there is a gap in understanding between these two sides.

I also feel that many Health Professional are aware of the gap but try to 'prove' that institutional racism was not a factor in this process. A conversation with a midwife in Scotland was very much along these lines. Her explanations were often such as to seem to 'protest too much…' Her protestations of adherence to systems that are overtly anti-institutional racist, for me, demonstrate how the NHS *is* institutionally racist. The system driven by the strictures of audit culture tries so very hard to be fair and even handed in all matters that involve minority ethnic groups, but this very act propounds this sense of 'other', no matter how positive the intention is.

I received an Excel data set, covering a political region in Scotland, extracted from the 1991 census. Among its workbooks was 'Other Data' in which was a column headed '% in Ethnic Groups (non-white)'. This I argue is institutionally racist. It lumps asylum seekers from Europe in with the 'white' population, yet separates a large proportion of Scots,[173] by the amount of *melanin*[174] in their skin. But in some areas institutional racism is not

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[173] Up to 0.57% according to the data.
[174] The chemical that pigments skin.

occurring. According to Alexander (1999) minority ethnic groups make up 6.21% of the UK population. Ethnic Pakistanis are the third largest ethnic group in the UK today. Minority ethnic staff working in Professions Allied to Medicine (an 'audit' title if ever there was one) account for 5.12% of total staff. But of this number only 0.19% is of ethnic Pakistani origin. This figure becomes even more disproportionate when one looks at nurses, midwives and health visitors – ethnic Pakistanis account for a mere 0.02%. My guess, and I have not met any ethnic Pakistani midwives to ask if I am right, is that this has to do with the fact that birth blood is *plit* (unclean, polluting) for Muslims. Most ethnic Pakistanis are Muslims; ergo Midwifery is an unclean[175] profession for Muslims. I suspect that that is a more accurate answer to the imbalance than a claim of institutional racism on this occasion.

In conversation with Health Professionals it was often suggested that the NHS worked 'top down'. That is to say, protocols and guidelines regarding treatment of ethnic minorities were cascaded from 'on-high' along with the other performance criteria and QA targets set by government. On one occasion I had joked about these with a manager in Scotland - only to have her point to a blue portfolio, the very document I had joked about. She laughed, but added (in a somewhat hushed conspiratorial tone) '…but then it's not turned into action, if you look around you're not going to see many Asian staff here. Yet there's quite a large Asian community in the area...' Though, as I said, midwifery may be problematic with regard to pollution for Muslims generally, I took her point with regard to the whole of the medical complex (hospital) in which we sat. With the exception of medical students, I cannot say that I have seen any 'South Asian' staff working in the areas I visited for this research, either in Riverside or Central Scotland. As my research has been working with South Asians and much of the contacts for the research being made via 'snowball', I have tended to notice South Asians within the general population much more than might perhaps be the norm. I postulated that the link between the university and the hospital together with the Pakistani side's keenness for educating their children, particularly in medicine, might encourage more applicants for jobs in the hospital from the ethnic

[175] Spiritually, not physically.

Pakistanis in the area. To which my informant said: 'There's not a lot, if you walk around the hospital you're no gona see a lot.' I said that I had read that there were only 120 nurses of Pakistani origin in the whole of the UK. This figure shocked even this somewhat cynical Health Professional.

CHAPTER NINE

THE NEW GENETICS

The New Genetics:

When I started this research one of the titles I thought of was *The Future is Out There*... – suggesting a science-fiction feel to genetics. However, as time passed - a relatively short time in the general scheme of things – the future rapidly ceased to be 'out there' and rapidly became 'in here', and seemingly with even more speed the future became 'back there'. What was held to be 'future' by key players (for example, Nobel Prize winning Prof. John Sulston and Lord Robert Winston, both of whom I met briefly during my fieldwork) in the initial stages of my work became fact, then 'ancient history' by the time I came to write the final draft. Legislation has tried to keep pace with the fast moving ebb and flow of the New Genetics, often without success. Or if there is success in 'plugging the dyke' that process or method is superseded by another – the yet unlegislated method of 'gene manipulation'.[176]

The ontological or bacteriological model of disease is no longer sufficient. Medical science, via the use of statistics, sociology and epidemiology, is able to predict congenital tendencies in populations. Thus it is able to look at the effects of poverty, poor housing, unemployment and overwork as factors contributing to disease. Now, with genetic screening, the opportunity to cure all ills is seen as the norm. The medicalisation [or perhaps geneticisation] of society has continued to such a point that nothing is seen as beyond medical science. This trend has led to the possibility for the dawn of a eugenicist's heaven – backed by mainstream orthodoxy. From a medical perspective any baby born with a disease or abnormality is a failure (Atkin et al 1998, 1640-49). From a eugenics point of view '...the dysgenic should be dissuaded from reproduction...' (Porter 1997, 640), which

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[176] In Israel eggs are being harvested from aborted foetuses for use in IVF programmes. There are major scientific and ethical and moral issues sufficient for several theses, all within this one simple technology. (BBC News 16/7/2003)

is one possible analysis of the 'treatment' (abortion of affected foetuses) of thalassaemia within the ethnic Pakistani population of the UK.

But is the new genetics the panacea some have made it out to be? I have visited Hinxton, Glaxo-Wellcome's contribution to the Human Genome Project, toured the Sanger Centre, seen with my own eyes the robots of the 'brave new world' (the 'sequencers' which looked like so many dishwashers) and talked to the scientists. I was put in mind of a post modern equivalent of the 'Emperor's new clothes'. Having the human genome mapped is far from having a cure for all of humanity's ills. Even when mutations are identified as links to a particular congenital disorder or a possible indication of a late onset disorder[177] there are few cures. In the majority of instances the only effective medical solution available to 'cure' these 'defects' is termination of the foetus. The scientist (Professor John Sulston), given the task of giving our group a guided tour of the Sanger Centre conveyed his excitement about his – and the Human Genome Project – work. When questioned as to when positive outcomes – cures for diseases – could be expected he was a little vague. When pressed his best guess was 30 years, but equally 300 years was also within the realms of possibility (also cf. BMJ 6/2/99, 341). Many others, including Professor Weatherall, Head of the Institute for Molecular Medicine at John Radcliffe Hospital, Oxford, have also taken this view. From this it is clear that it is not the scientists – even though they are excited regarding their research – who are 'over-egging the pudding' in regard to the current and future state of genomic research but others outwith the field, for example trans-national drug conglomerates (Porter 1997, 660, 662-3, 668-9) and the ever-burgeoning genetics laboratories in the private sector (BMJ 6/2/1999, 341; ESRC 2005, 15, 19) – not to mention the claims often made by the media.

The media are proclaiming the '…whole human genome is now mapped…', with headlines such as 'Workshop Manual for Human Body' or 'Blueprint for Life' completed, raising the hopes of the general public (Cookson 1998). Sulston said that to some extent these claims were true, but what had actually been achieved was the 'fuzzy genome', it

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[177] Alzheimer's or heart disease

would be perhaps a further three years until the human genome came into focus. Then, and only then, could work begin into making practical applications of the research. The reality is that after twenty years of research not one single practical genetic cure for *any* disease has been found.[178]

The much vaunted New Genetics heralding a new age of medical science – the panacea of 'recombinant DNA' – is currently merely a myth created by journalists and politicians (cf. Cookson 1998). Yet the public's perception – and perhaps more interestingly that of Health Professionals – is that DNA and genetic testing are the proof that illness is soon to be a thing of the past. Porter quotes American writer Harold Brodkey, an AIDS sufferer, who declared, '…I want [President] Clinton to save my life…' (Porter 1997, 630). This is indicative of the widely held belief that medicine is both scientific and effective and of the fact that people have become beguiled into a sense that medicine is the 'Fairy Godmother' granting everyone's wishes (cf. Porter 1997, 630). There has been a gradual move, since the beginning of the twentieth century, towards preventative medicine, via testing and screening health initiatives. Why wait for people to become sick before intervention, medicine should be proactive. But as Porter so succinctly put it:

> 'Earlier optimism about magic bullets and a pill for every ill now seems symptomatic of a shallow high tech, quick fix version of the world, born of the laboratory and expecting the world to be as controllable as a laboratory'.
>
> (Porter 1997, 711)

Many have suggested that approachable explanations and attempts to get the public involved in the debate, rather than falsely raising public expectation, offers a more useful way forward.

I asked Freda, a midwife in Riverside, her opinion on the application of genetic cures, which were set to come on-line in the near future. She was somewhat wary, and commented:

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[178] Thalassaemia is curable by bone marrow transplant – various methods are available for gaining compatible donor marrow – but to what extent this is practical is open to debate. The only certainty is that until there is informed public debate on these genomic relayed issues then discussion is likely to continue to be driven by sensationalist, and more often than not ill informed or wrong, media debate.

'... scientists, people and the medical profession are getting too excited with this whole concept of being able to intervene in this way...But 'genetics' has not been around long enough for people to see the affects, it's like that thalidomide... they thought it was an absolutely *brilliant* drug to reduce morning sickness, yet it hadn't been properly tested for all its possible side effects... I don't think people know enough about the consequences...'

On the one hand parents are pushing for the courts to sanction some form of genetic intervention to save their child[179] and on the other some front line Health Professionals suggest that we should be erring on the side of caution.

There is clearly a mismatch between what Health Professionals and their clients expect and understand of genetics and the purpose of genetic testing. For Pakistani parents their interest in genetic tests is perhaps to make provision for a child which is to be born with an illness (Atkin 1998, 1645-46).Yet, from the medical professional's point of view every child born with thalassaemia, or any other genetic abnormality, may be seen as a 'failure'. This seems to encapsulate the dichotomy of the medical versus the social model of health, in microcosm.

Perceptions and understandings of 'genetics':

There are many different ways that 'genetics' are perceived, understood and experienced. These perceptions and understandings do not fit into a simple lay/professional dichotomy, very much as I had suspected at the start of my odyssey. Way back at the beginning of my research I engaged in conversation a locum from the recently subsumed East Germany and asked him for his opinion of genetics and genetic testing. He said that regarding late onset disorders and genetic diseases for which there was no likelihood of a cure, he personally would much prefer not to know. A manager of a large antenatal clinic in a major teaching hospital told me that genetics was fascinating, but added that she

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[179] The Hashmi family, for example, where a cure revolved around preimplantation testing of a sibling foetus. (BBC News 22/2/2002).

understood little of it. She commented that she had '…a couple of books up there (pointing to a shelf over her desk)… It's very interesting, but…' I suspect that very much sums up the view of the vast majority of the UK population, lay or Health Professional. I talked to several GSMs and they also found that it was almost impossible to keep abreast of all significant genetic information - even with twice yearly meetings and specialist training.

Kath, GSM in Poundtown, felt that the quality of life for patients and their families (if affected by thalassaemia major) was very poor. We discussed the time consuming-nature of treatment with daily processes (chelation pumps etc), visits to hospital for blood transfusions and consultations and other ancillary interactions with the health system. She also felt that parents conceived of the birth of an affected child as perhaps a test from god - the 'Will of Allah' – and as something they could cope with, via the extended family. But any indication (via prenatal testing) of an affected foetus was usually viewed, by the couple, in a different light. Most opted for termination, although some continued to see it as a test set by Allah.

There are two possible routes with regard to the detection of haemoglobinopathies – haematology or genetics. I asked a midwife which one applied most frequently, in her experience. She said, 'It was the haematology pathway really.' I speculated that this may have implications, as haematologists may tend more towards the biomedical model[180] of illness, rather than the social model likely from a trained genetic counsellor. One key issue that I felt was important in this process was a positive discussion of the adaptive mutation that causes thalassaemia, rather than one that suggests that people are at fault at some fundamental level of their being – their DNA –without any options to make things better. When I explained to Freda, a midwife in North Shore, about the protection this adaptive mutation (thalassaemia trait) gave babies, in the first six months of life from malaria, she was surprised and commented, 'Well that's something…' Up to that point she had perceived thalassaemia as simply being a disease in need of eradication. I asked her what her thoughts

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[180] This was before my discussion with a senior haematologist in Scotland whose attitude was clearly very person centred.

were in regard to the biomedical need to 'cure' all divergence from the standardised human. Freda commented, 'Yeah, a little box that everyone needs to fit in.' Her perspective is also coloured by her experience of genetics on the personal as well as the professional level, which I discuss more fully later. I suggested that Health Professionals in many cases did not understand the implications and issues, particularly those surrounding risk, in this area, even with specialist medical knowledge and training. If this is the case then how much more difficult for lay people to grasp what is being said in regard to risk, at-risk, risk avoidance and risk management. The midwife said that was often the case, people had differing perceptions of risk. Her encounters with lay people, she felt, may also be skewed by her professional training and the milieu in which she operated. That is to say the biomedical and not the social model of health and illness was her usual realm. I told a midwife in Riverside that I had recently read an in-house medical text[181] concerning guidelines for the termination of pregnancy in the case of foetal abnormality and found the terminology somewhat disconcerting. She laughed and said that that was often the case, medical authors were often detached from the common sense view of the world that most of us lived in.

There are many genetic diseases like thalassaemia, for example cystic fibrosis (CF), which stem from a single gene. In an article about her niece actress Jenny Agutter discusses some of the issues around CF, for which there are parallels in the findings of my research into thalassaemia (Agutter 2003). Agutter talks of risk, saying that we can all say 'Live for the moment… because we could be run over by a bus'. However, Agutter suggests, most of us do not believe there is a risk of that event coming to pass. Such cognitive dissonance is almost certainly present in parents faced with the results of a genetic test.

Agutter believes that this means that CF will be '…the first genetic illness to be cured.' Agutter explains that in gene therapy faulty genes are replaced with normal ones (again, this sense of the normal and abnormal with regard to genes) – it has been done in mice already. Finally, Agutter tells us that, 'In April 2004, the screening of every child at

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[181] Royal College of Obstetricians and Gynaecologists 'Termination of Pregnancy for Foetal Abnormality, in England and Wales (January 1996)

birth in England and Wales will be introduced, as in Scotland.' I would make two comments here. The first is that such a test, if positive for CF, is too late to make any difference but merely indicates the treatment needed to keep that individual alive for the rest of their lives. Secondly, if my finding with regard to the National Screening Programme for the Haemoglobinopathies is mirrored in CF testing it will be patchy at best and a postcode lottery at worst. Agutter seems to have faith that the technology will save her niece.

A mother in North Shore similarly hoped for a cure for thalassaemia – but rather than faith in genetic engineering she believed in Allah. Her father died recently after suffering from Alzheimer's disease. Parveen was convinced that the disease and subsequent death was the '…Will of Allah…' and could not have been prevented. This fatalistic view of life, marriage and death is also reflected in this ethnic Pakistani woman's attitude to genetic disorders (of which Alzheimer's is one) and poor birth outcome. There is a contradiction here; this particular woman has advocated education and highlighted the need for public discussion of genetics and genetic risk, yet for herself she submits to the personal fatalistic perspective that says that '… the 'Will of Allah…' cannot be challenged.

Parveen and I talked of the possibility of an increased risk of thalassaemia resulting from marriage between cousins. She was most keen to point out that birth defects also occurred '…in white families too…' Clearly this is the case as we all carry around twenty serious recessive mutations in all our genes. There is also no reason to see the haemoglobinopathies as a uniquely 'non-white' disorder, particularly with the increasing globalisation of society in the UK. I felt that I should point out to the woman that thalassaemia was a very useful, perhaps even crucial, adaptive mutation when viewed from the South Asian context. She thought there was a tendency for Health Professionals (and researchers) to stereotype genetic disorders as being linked to cultural shortfalls in minority ethnic sides.

Contrasting views to Parveen were notably held by the Imam and *hafiz* I met. One Imam, Mr. Kalum, told me that the debate in which I wish to engage was current and

'...needed to be brought out into the open...' He was most supportive of my plans to be involved in preparing a booklet and video,[182] to that end. He also said that:

> '...many Muslims did not understand ' genetics', but it is clear, in the Qur'an, that it was wrong to have a sickly baby, knowingly. If the knowledge was not there, no problem - it is Allah's will. But if you knowingly marry someone [here he was talking of the practice of FCM by ethnic Pakistanis] who you know would give birth to babies who were ill it is wrong. The whole point [of Islam] is to make the best for children...'

This view was common, even ubiquitous, among the Imams I talked with. It was equally clear that the views of the Imam were, very often, not shared by all of their 'flock' (see also Eickelman & Piscatori 1996, 38).

[182] This has not been done as I am no longer certain that the views I held at the outset of this research remain valid today.

Part Four

Risk Enacted

CHAPTER TEN

AUDIT/RISK ENACTED

Audit/Risk:

In this chapter, considering both ethnic Pakistanis and Health Professionals, I shall consider the role of audit in amplifying tensions within each side, and between the two sides. This is the context in which the combination of thalassaemia, FCM and matters of inter-personal communication has put both sides at-risk. We shall see that by Health Professionals audit is perceived in a very negative manner. I look at how individuals see the problems within the system and look for possible solutions; for these individuals audit is seen as an ongoing process for reflexive discussion. I suggest that my exposition is not only relevant to the specific populations that I discuss in this thesis, but has implications for wider application for British society. I had thought to use the word *performance* in this chapter, as a descriptor the operationalisation of audit and risk by my informants, suggesting links with the language of audit with its talk of 'performance criteria'. However, 'performance' is also a loaded anthropological conception and one which I do not wish to suggest here. When I use the word performance I am merely talking of the actions and enactments carried out by individuals and groups in relation to my research topic.

Best Practice:

I was curious about one of the key concepts of audit, best practice, and the implied positivity that the term conjures up. For example, was there any conflict between the individual care packages espoused as a key NHS objective, and the importance of meeting targets? One Health Professional, who had been a midwife for about twenty years, made the following comment regarding best practice: '…people have different views of things. What you think is best practice others might not agree and vice versa…' She continued by telling me that she felt everyone was '…being shepherded down the one line and being told "Well, we think that that's best and so that's what you've got to do."…' I began to get a sense that best practice was not quite as positive as it first sounded.

I asked what had happened before the introduction of the protocols and guidelines? The midwife said: '…the way it always used to happen was you talked to people (other midwives) and asked "What do you do in this situation?" "Oh well, actually, you know, I've got this, that and the other." "Does it work well?' And people would adapt things like that…' I said what she was describing was a training system often called 'Sitting next to Nelly'. That is a new employee was sat next to the 'old hand' and was 'shown the ropes'. There was continuity, and standards were maintained to the required level. She laughed at the phraseology but agreed that that was precisely what she had experienced when starting out as a midwife. A somewhat more person-centred milieu before the full effects of the Thatcher Revolution took affect. It is also clear from what she said that there is in implicit threat or risk in non-compliance to guidelines, which was not there in the past. The midwife further commented: '...But now it's, "You've got to do what you're told to…'

This view of contemporary midwifery was exactly that described by other midwives and GSMs on both sides of the border. Strathern et al (2000) demonstrate the pervasive and global nature of audit culture and suggest that there is not a country on Earth where it is not to be found. This being the case, one should not be surprised that this chronic 'disease' presents in both England and Scotland.

I asked other Health Professionals whether they thought that this situation interfered with patient care. Whilst boxes were being 'ticked' did patients suffer as individuals? Many of them agreed it did. One midwife commented: 'You are no longer dealing with individuals, you're doing things because you're told to do them. … it's funny you say that "ticky-boxes…" our booking-in interview papers like that [holds up a stack of papers scooped from the desk top] are ticky-boxes literally.'[183] Her comment suggests that the individual careplan is indeed being sacrificed at the altar of performance criteria, that audit

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[183] Note: This need for audit may well be a major factor in poor retention of nurses – they prefer agency nursing (see news bulletins from 18/19 March 2004). NHS trained nurses prefer to leave the NHS and work for private nursing agencies.

protocols are carried out under duress and the patient is put at-risk. With regards the booking-in process:

> '...you get very, very much stuck onto those levels and you can't sort of deviate away from it at all. If it's not written in those "ticky-boxes"... If there's something completely different then people don't think to say to you "Well actually I have this or I had that." Because it's not something you've come up with they don't think to, like to sort of say to you "Well that's what I actually need"...'

A specific point that came to my mind here was the observance of Muslim ritual and adherence to Islamic practices regarding issues of pollution. I was given a copy of the booking-in form; nowhere is there any opportunity to discuss these needs specifically. The midwife continued:

> '...Which makes it more difficult. You're not treating people as individuals, although you're supposedly going along [with the idea that] this new scheme of everything has got to be tailored to that one person it's [called] an individualised care package, but because you're lumping it all together you can't possibly do that...'

I asked if she felt that if she operated outside the 'guidelines' and a patient sued, the Health Authority would not finance the defence of the individual or provide funds for any compensation. She said:

> 'Yes. And if there is any problem and they sue you then it's your fault cos you've not followed what you should have done.'

This last sentence was said in a very sad and somewhat dispirited tone of voice. I had a very strong sense, both at the time and when re-listening to the tape-recording, that this was a very real and felt threat to health practitioners at the 'coal-face' of health provision within contemporary UK health care. Audit culture was itself perceived as a risk, by Health Professionals. In this sense risk informed their actions in conveying risk to the patients in

their care. Risk, in a very real sense, regulates the practitioner in their interaction with patients. Audit and risk are inexorably entwined at all levels.

I asked Kath, another midwife, to comment on how she thought audit had impacted on her role as a midwife. She said:

> 'Errm [long pause] [throat clear] I think your views change over the time you work for the NHS cos I think you get *indoctrinated* by it really. Errm [pause] and so I think the more you work within the NHS then the more, the more your views sort of go along those ideals. But errm [pause] I think [pause] when you're, when you are actually on the other side of things [pause] looking in then you can see where the problems are…'

My question had clearly caused pause for thought, and no small conflict in the mind of this particular midwife.

My take on this uncertainty was that she was reflecting upon what she did in her normal daily routine as a midwife as a professional and thus part of the team and her personal experiences as a mum-to-be. During her last pregnancy she was worried that her daughter may have inherited a genetic mutation which, if she was given the standard vitamin K injection shortly after birth, would result in her becoming extremely ill. She had a not too uncommon experience with her doctor's attitude which was very dismissive;[184] even though she was a trained and qualified midwife her concerns were ignored. So she spoke to a (female) obstetrician whom she had worked with previously. That 'friendly' obstetrician then interceded on her behalf and spoke to her then obstetrician to explain her concerns in regard to the feared genetic abnormality and the need for DNA testing at birth. Now her doctor found that she was no longer 'in-the-team', and came to perceive her as an 'outsider', a 'woman', a 'patient', but no longer a Health Professional.

I asked midwives if they felt that the job had become more about 'ticky-boxes' and less about a person centred relationship between midwife and mum. I also asked their opinion on a health service based on issues of quality assurance - was it drag-down the best,

[184] Oakley (1986) and my informants' experiences.

and drag-up the worst practitioners. One Scottish midwife commented, somewhat wistfully: 'If you're lucky' [Laughs]. I said I had gained the impression that some sort of 'robot' culture was developing. To which I was told:

> 'I think we are going along those lines a lot of the time because there are so many protocols or procedures that come out and you've got to move within those. And if you *deviate slightly* from them somebody from higher up is coming down to, to *slap you down* and say, "Well no, you've got to carry-on on things at that level" and "This is what we told you because we've looked at everything and *we've* decided this is best practice".'

Again there was this concern that the aims were not being met, just the measured outcomes.

A senior midwife spoke in similar terms. She told me:

> '...they're supposedly *guidelines* a lot of them. But they're not guidelines because if you veer off them then *they* drag you back to them and say, "No, that's not right we've got these guidelines and that is what you've got to follow." And I think it's becoming more and more like that. Much of the time we are told it is to avoid litigation, but some people use it as an excuse – to make their job much simpler...'[185]

I noted already that many midwives see a clear and present risk if they step outwith the guidelines. It is interesting that one of them noted that the threat of litigation is being used as an excuse to enforce compliance. But I also got the sense that she was also saying that colleagues were using this as a way of avoiding offering more diverse options to women - becoming more jobsworth in their interactions with perhaps awkward patients (or awkward as defined by the Health Professional[186]).

Audit is sometimes used as a way of keeping 'secrets', or, rather, hiding from scrutiny by outsiders – me, for example. An example of audit as shield was seen when a GSM was

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[185] We are told that there is an increase in the litigious nature of the UK population, but I am not sure this is the case. If there is why is this occurring? Greater incompetence, too ridged guidelines or just people taking the opportunity to get 'revenge' against the mindless bureaucracy that is 'audit culture'? Perhaps this is an area that would warrant further investigation in a future piece of research.

[186] Compare Ahmad 1994; Proctor & Smith 1992.

somewhat obstructive in my attempts to observe interaction between the ethnic Pakistanis and Health Professionals in the Clinical Genetics Department in a large teaching hospital. The GSM argued that there were issues of patient confidentiality: her concern was for *her* patients. The geneticist could see no real problems with my observing sessions, with prior notification of patients and with process consent[187] in place. He was particularly interested in what the patients thought was happening at such encounters. However, as the discussion heated up the GSM said:

> 'A lot of them disclose things; I want them to disclose things to me, about what their concerns are. I don't want there to be anyone else there. I would always be cautious of anyone else in the room.'

I strongly suspect that she did not want a witness to her individual interaction. No other informant voiced this particular concern and I suspect that it was a sense of personal insecurity, not concern for *her* patient's confidentiality that was the motor for her concerns. Fortunately her closed attitude here was not common.

Informed Consent:

A related area I was interested in regarding the processes involved in counselling and testing at-risk individuals was informed consent – a key audit requirement. One GSM talked of checklists and setting out the information in a language and in terms that the patient could understand. However, when pressed for evidence of this she began to reflect on whether she was only meeting requirements set in place to prevent litigation and blame and that perhaps true informed consent was beyond the reach of the NHS.

Jane, a GSM, told me that she gives the patient all of the information, trying to pitch it at an appropriate level for the individual patent – which she says is quite hard as she has to make snap judgements about people. Sometime she gets it wrong and this makes her job more difficult. She said that she has books and videos which she uses to help the patients understand the sometimes quite complex issues that arise from the subject of genetics and

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[187] The informant is asked before every encounter whether they remain willing to participate in the research. The additional safeguard of having their data removed from the research, without prejudice, at any time should they have a change of heart is also part of the consent process.

genetic risk. As for informed consent she asks the patients if they have understood. Often asking them questions to see if they have retained the information imparted and, more to the point, if they have understood it. When this process is completed she gets the patients to sign a form to confirm that they have been given the information and more importantly that they have understood it. There is also a check-list that she uses: '…I make sure that there is evidence if ever the patient complains that they were not informed and it also acts as an *aide-memoir* to make sure I leave nothing out…'

This apparently simple process has so many complex issues encapsulated within it. The snap decision about a patient, mostly based on phenotype one guesses, as the couple enter the consulting room, as strangers, and sit down. Having made this judgement information is then downloaded – at the appropriate level. Clearly mistakes are made and informed consent is in this sense put at-risk. The books and videos are somewhat intimidating of themselves; in addition our media based society predisposes us to accept 'facts' in this medium. Asking the patient if they have understood, and ensuring that learning has taken place via question and answer is a flawed process. When one takes into account the cultural predisposition within the ethnic Pakistanis side to answer polite questions positively this process becomes even more suspect. Finally, the patient has to sign a document to say that they have been given both all necessary information and that they have understood it. They have to trust the Health Professional in this, they are not qualified to know if this is so. This signature is then seen as proof that understanding has taken place and that informed consent has been given. This protocol is claimed to be in the patient's best interests and for their protection. The reality is that its purpose is to ensure a legal protection from future litigation.

Institutional Racism 'operationalised':

A lead midwife I spoke with in Central Scotland was keen to know how the health service could find solutions to the issues which led to institutional racism. I suggested perhaps doing nothing might be the best policy. She then said:

'...We try; it's maybe a '*nursie*' type thing that we try to fix the *problem*. But sometimes we need to learn that all we should be doing is trying to create an environment where people will feel able to do their own thing.

So I suppose instead of us setting the tone for communication with these Pakistani women. If we could work out how we do the neutral thing and allow them to come to us with a level of communication...'

I suspect that this is at the very root of the tension between these two groups. The institutional racism does not flow from an uncaring callous NHS but rather from one that cares too much - but cares in an inappropriate manner. Both sides are forced into compliance with a system in which neither is comfortable. The same informant told the following story which illustrates my point.

'I'm thinking of a lady [South Asain] I visited...Every day we went in to check her daughter who'd had her baby. That this poor lady... a little old woman she... came trundling in with a... wooden dinning-chair. Into this tiny little bedroom... she manoeuvred this chair...until this chair was set beside the bed and then I was asked to sit on the chair. I sat there because she had gone to all this bother. We were never sure if it was that the granny thought that this was what we expected of her or whether this was something that was very important to her.

I didn't know if I'd be rude to say, *"Forget the chair I'm only here for a twenty minute visit, I've got things to do."* I thought is she thinking I expect a chair...

And I suppose it's how we get to the point where our communication could be such that we could each be honest without offending the other and so on.'

This story demonstrates the point that I am trying to make in my thesis – to paraphrase Bruce Lee *'the art of doing without doing.'*[188] Yet the highly professionalised NHS has made it well nigh impossible to do nothing. Everything is set to meet performance criteria and measurable outcomes. I suggest there is a need to step back and ask why is this being

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[188] Bruce Lee in 'Enter the Dragon' (Warner Brothers 1973)

done? Who are we doing it for? I suggest the answer should be 'the patient', but more likely it is found to be externally set targets.

The lead midwife said, 'It's a defensive thing.' She then told me that if people (Health Professionals) failed to 'go by the book' then insurances could be voided and the individual left to their own fate - '...then you're on your own, kind of thing...' I then commented that a committee was likely to be formed to which she commented '...and try to fix it...' I then said that there would then be a need to 'fix' the 'fix'. She agreed '...and so it goes on...' I pointed to the shelves of portfolios around the office and said that I had no doubt that they were filled with the very 'fixes' that we were hypothesising on. She replied:

> 'It is, Aha. Wisdom from on high ...This is the way you should treat this patient, with this kind of disorder. And all your protocols should reflect this *guidance*. And then it's paperwork to *prove* that's what we actually *do* cos we do audit there is a lot of that in there that will be audit papers that staff have done to *prove* what we actually do here. You're right, so it goes on...'

She reflected that:

> 'I suppose we're as bad when you go back to your Pakistani women because you, you tend to remember your first experience with somebody from a different background to your own. And you kind of make assumptions based on that. So your behaviour is based on this one experience that you had maybe years ago. And there's no way you would expect every white couple that comes through the door to have exactly the same circumstances and need exactly the same approach. Yet you tend to formulate an approach that you would use for women from ethnic groups, be they Chinese, African or whatever they are.
> I suppose the only thing I would say in our defence that it's better than maybe what went before which was that we caused a lot of real distress to people because we really did'nee care. The one thing you can say is that people care sufficiently [laughs] to at least make some kind of effort.

> But whether that caring is based around protecting their own backs or whether it is trying to avoid a bad experience that they feel that they might of contributed to in the past I don't know. *We're not getting it right*, but hopefully we're getting better.'

I suggested that the increasingly person centred approach may well be the way forward, but that this would take a considerable time to bear fruit. I said I did not see that as happening 'by next Wednesday'. She replied:

> '…Not at all, not even by two-thousand and twenty-two I suspect…' [Laughs].

I think that she hit upon the essence of the problem when she said:

> '…I think the other issue is that we don't have enough practice. We're not having enough of these interactions to become good at it…'

The other point that was made, and I think it is a valid one, was that ethnic minority groups keep to themselves, often bring their own food in for their relatives. Also the Health Professionals tend to stay on the periphery and just do what they absolutely have to do for these women, assuming that they're getting the support that they feel they need from their family (Murray: 1998); so Health Professionals do not get enough practice in interacting with these people. Quite often, due to protocols on dealing with minority ethnic groups, it is easy to forget that the reality is they are British and should be treated as such, that is as individuals whose practical and cultural needs should be enquired into and not presumed. I was also told that the NHS don't have enough follow-through and enough time to sit down with people and say, 'Well, you came to our service, what was your experience like? How could we have made that better for you?' They don't have the luxury of doing that with anybody, but particularly with ethnic groups where communication perhaps takes time. I was put in mind of a line from Gattaca (Niccol 1997) which sums up the interaction here between the two sides:

> 'They have got you looking for a flaw, any flaw, so after a while that is all that you can see…'

I suggest that the NHS's attempts to avoid seeming to be institutionally racist are, in many instances, the problem, not the solution. Pakistani informants I had spoken to only wanted to be treated the same as everyone else. I see that protocols are problematic in this situation where attempts are made to be even-handed and non-racist – but are essentially triggered by levels of melanin and dress choice. The lead midwife stated that protocols, '…make you behave differently [nervous laugh] absolutely, yes.' Here is a midwife with more than twenty years of experience who feels that she now behaves in a dismissive (and different) manner depending on the patient's perceived ethnic origin. It is not that she is a racist, it is that she has to follow protocols because not to do so will have negative consequences.

Islam 'performed':

There is a sense that Islam is 'performed', mainly by men, for the benefit of the 'outsider' audience, in this instance me, but also for 'insiders' - mostly Muslim women. By this I mean that certain lay individuals (I stress 'lay' as I did not observe this in my interactions with Imam), represent their religion to create an image that is not a true representation of Islam. The representation of Islam, by many ethnic Pakistani men, is the same, whether it is for me or Muslim women, and its purpose is to exert power and control. What follows is one such enactment by a Muslim medical doctor, and a group of men, at a large mosque in Scotland.

The Muslim doctor's narrative:

I have described how Imam have viewed my research and how they understand the *Qur'an* in relation to abortion and FCM. I spent several days at a mosque in Scotland where I spoke to many Muslims. One day I was invited to meet with a group of men, one of whom was a medical doctor at the local hospital. I was told that he would explain how genetics was understood in Islam. What follows is what a Muslim medical doctor told me about issues around FCM, abortion, foetal development and genetic issues in general. It reflects the fixity of outlook which I have encountered with other educated Muslims. A rigid and unbending

outlook which intertwines Islam and science to the glory of the former that I have not found among either working class ethnic Pakistanis or the Imam that I have met.

When I entered one of the side rooms at the mosque there were ten men already in the room. The men, including the medical doctor, told me that they were involved in developing an educational presentation for delivery to the local schools when they came for visits to the mosque. I introduced myself and gave a brief overview of my work. I began to talk about DNA and my visit to the Wellcome Trust's Human Genome Project, at Hinxton. I was interrupted by the doctor who began by talking of the very specific sequences of DNA that are necessary to create living things. He argued that only Allah knew what these were. I remained silent about Crick et al, I was interested in his understanding of genetics. He continued by explaining:

> 'If you have a mutation, even if you have only a one point mutation, you have a fairly different things. Now the chance of a protein, not a human being, not even a small organism, just a one protein coming by a chance is almost about one in billion or ten billion... There is a slide here that tells you the exact figure. One of the scientists worked it out.'

This statement was indicative of what were to become an all too familiar argument in the hours that followed. At times clearly self-invented statements were attributed as sayings of the Prophet (PBUH). I was told that nothing that ever was, is or ever shall be is not in the *Qur'an*. Including mobile phones – I was told, by the doctor, that the Prophet (PBUH) had told his followers that one day men would have talking sticks, clear proof that the Prophet (PBUH) was aware of microwave technology in the seventh century CE[189] – this 'fact' was agreed to by all of the men in the room. At this point I wish to make crystal clear that I have the utmost respect for Islam and all that that entails – my issue is with men who propound their own foolish ideas and attempt to legitimate their claims using Islam. All of the statements the doctor made were either 'proved' by verses from the *Qur'an* or research done by 'scientists'. However, no scientist or group of scientists were named, nor were the

[189] Common Era

references to the *Hadith* given and only rarely given for the *Qur'an*. Thus the doctor constantly conflated scientific terminology and religious references to prove every point he made. The doctor continued his explanation: '… that is for a protein. So to say that things has happened by chance – it is very, very difficult to stretch of imagination, beyond belief [Laughs].' The use of popular appeals and persuader words was also employed to convince me of the validity of the argument.

I agreed with the doctor that DNA seemed fairly implausible. Even though I had seen the machines at Hinxton I still had to take it upon trust that the scientists were telling me the truth. I attempted to discern how genetics were conceptualised or imagined by Muslims. The doctor continued by telling me that:

> '…Even if you put things in a disorganised way on a table and leave it for hundred thousand years and you come back here it will still be same, or even more disorganised not less disorganised. So, leaving things, mutations in fact produce disease and harm more than they produce improvement.'

I then asked him how this argument fitted with the case of thalassaemia which provided an adaptation which protected children from dying of malaria in infancy. The doctor replied:

> 'Well what I am trying to say is if you take a normal human being and a thalassaemia [a human being with thalassaemia] which, which one has a defective gene? It's the thalassaemia has the defective gene…'

I attempted to change tack and suggested that, for some, genetics had become a form of religion, that is to say that doctors and patients begin to see genetics in this way – all-powerful and life changing and as offering explanation for individual susceptibility to most disease. The doctor replied:

> 'They [geneticists and doctors] even tell us that gay is specific genome…So if you look at the evidence, there is really no evidence so if we accept that evidence we accept everything… [Laughs].'

It was clear that the doctor was only prepared to accept scientific evidence that did not conflict with his interpretation of Islam. Anything else was immediately dismissed as false. I tried again by asking the doctor's views on thalassaemia within the South Asian population and how his view might affect the receipt of medical advice which could potentially result in parents opting for termination of the foetus. Did he think that perceptions of risk and understandings of genetic mutations might be influenced by belief in Islam? What about perceptions of blame, perhaps seeing thalassaemia as being someone's fault – perhaps DNA could be viewed as the ultimate panopticon? The doctor ignored my point and launched into another 'sermon'. The general consensus, in the room, was that:

> 'You can find anything in the *Qur'an*, any solution, any answer to your questions – all answers in *Qur'an*.'

This view was vocalised by an old man, but the others all nodded their agreement with this sentiment. But nobody commented on my questions, least of all the doctor.

I then attempted to access the group's views on other applications of genetics in the hope of opening up the debate. I asked the men about their thoughts on the use of stem cells from the umbilical cord of a new-born child being used to treat/cure sick siblings. Not creating new life but certainly modifying, at a most fundamental level, the life of an individual. The doctor said that the case was similar to in-vitro fertilisation (IVF), if there were medical problems then medical intervention was permitted. The doctor continued:

> '…you're, you're just applying the knowledge - this brain has been given to you from god - to do things in the right direction. It is universally accepted by Muslims that we should be able to do that. The things that, for example, using cells to try and modify and help [cure] diseases, there is no objection to that what so ever. So anything good for humanity, anything good for the health the [people] is accepted…'

I then related conversations I had had with the genetic counsellor in Citadel (see below), particularly the ethical issues around gaining informed consent from a child or pressure on

siblings to 'do the right thing', as was the case with, for example, bone marrow transplantation. If stem cells were used with the umbilical cord discarded in any case shortly after the birth, this avoided these ethical problems and even allowed the child to do good for another, by simply being born. I asked if this analysis was acceptable, from an Islamic perspective. The doctor paused for a considerable time before beginning to answer. Again the doctor ignored the question and continued his sermon in an attempt to avoid answering the question. This sermon continued for some considerable time, I was offered proof upon proof that the *Qur'an* was scientific. We eventually arrived at the embryo section of their slide presentation.

At last we came to the discussion that I had been invited to witness – an account of Islamic knowledge regarding foetal development. The doctor explained, using PowerPoint slides, the standard description of foetal development from a Quranic perspective. First of all he described the Muslim creation myth and explained that the constituents of clay and human beings are essentially the same, proving that Allah made Prophet Adam from clay, as we are told in the *Qur'an*. The first stage of foetal development is '…as a drop in a safe lodging…' - the male and female sperm and egg '…a mix of the two, the zygote…' – '…in safe lodging…' – the uterus. At the next stage of development the droplet becomes '…*alaqa*' (leech, suspended thing or blood clot – Ibrahim 1997, 6). The doctor then said: 'Then we [Allah] make the *alaqa* into *mudghah* '- *Mudghah* means a chewed-like substance (Ibrahim 1997, 6). Finally (the doctor reads from the script accompanying the presentation): '…"And then we [Allah] made *mudghah* into bones and we [Allah] clothed the bones with flesh".' This is again in complete agreement with scientific understanding; the bones are the first thing to form, then the tendons and muscles clothe the bones. "And then we [Allah] clothed the bones in flesh. And then we [Allah] brought it forth as another creation." (This final part is agreed by all Muslims as proof that Allah created man, and thus disproving evolutionary theory). I asked if the various stages the doctor had described coincided with the forty-day periods. The doctor said that he could not remember exactly.

The doctor was hesitant at times in his explanations, trying to justify the Islamic perspective and make it sound like scientific fact. It was clear that everyone in the room, with the exception of me, was quite happy to except this pseudo-science as both scientific fact and scientific proof of the authenticity of the *Qur'an*. For them, this discussion was not about biology but a scientific proof that their religion was true.

This was not the first time that the 'science' of the *Qur'an* had been used by Muslims to explain their world view to me. However, it was the first time that I had heard this sort of explanation from a man who was trained as a medical doctor. I have no doubt that taken at face value the Quranic description of foetal development is plausible. After all, North Africa was the repository of learning during the Dark Ages in Northern Europe. The mathematical concept of zero was developed by a Muslim at this time. However, this twenty-first century scientific sleight-of-hand I was being offered was something of a surprise. The lack of sophistication in these explanations offered by a medical doctor, when compared with the complex discussions I had had with take-away food purveyors in Riverside, left me astounded. Furthermore, I doubt if the Imam would have agreed with this dumbed-down explanation of issues that were vital in understandings of current concerns, and debate, in relation to genetics, thalassaemia and FCM for ethnic Pakistanis.

If a medical doctor can hold such views, supported by all of the men in the room that evening, then it is not difficult to see how Pakistani Muslims may perceive information given to them by doctors and midwives in regard to genetic disorders and options to terminate such pregnancies. Their religion has in-built 'scientific proofs' and thus science and religion are one. If this is the case then there must be a very strong possibility of an even greater deference to science and medicine than that held by non-Muslims in contemporary UK society. This also suggests a potential inbuilt argument against a medical model explanation of thalassaemia as an adaptive mutation.

So I turned to thalassaemia as an adaptive mutation relating to malaria. I suggested that many of the men in the room may not have been born were it not for this. The doctor

made noises of agreement as I made each of these points and then said: 'But you see this is our resistance to the infections that…' I briefly described how this mutation worked by instructing smaller, more numerous, red blood cells. The smaller cells had less iron available and thus the malaria vector was broken. The doctor then said, 'So, so it is a way adaptive to keep the people healthy?' The medical doctor did not even have the basic knowledge about this mutation. This was problematic as it was likely that he would be the one consulted by the men of the mosque in these matters – he had been introduced, as an expert, to me to discuss this very subject. So if this is the view of a medical doctor it must be an uphill struggle to discuss genetic mutation with a lay Muslim couple.

The medical student's narrative:

Asiff, a third year medical student, who was also a member of the Islamic Society at the university, agreed with my basic outline of foetal development, which I had taken from the *Qur'an*. I then said that I was interested in talking about his understanding of ensoulment. Asiff looked more and more worried as we talked. I got a strong sense that he was unaware of much of what I was talking about. His only comment was the odd 'Yeah' now and again. He then commented:

> 'I'm not too sure about ensoulment to be honest. I'm not sure but I have the feeling that the foetus is ensouled after forty days, rather than a hundred and twenty you mentioned. But, the thing is like did you get these from the English translation?'

I replied 'Yes.' Asiff continued, somewhat more confidently:

> 'Yeah, because you've got to be a bit *careful* because like unless you understand the *classical* Arabic because it's very easy to interpritate [misinterpret] because like you have one word that means nine, has nine meanings to it in Arabic, you know.'

This was what by now I recognised as the standard defence from Muslims who were less 'learned' than I appeared to be regarding the *Qur'an*. I countered by saying that the author I

had read could understand classical Arabic, and also said that the 120 days seemed to be quite widely accepted, certainly by the Imam and *hafiz* I had talked with. He remained unconvinced and told me he would check it out '...down the mosque...'. Again another common defence which was not unlooked for. Many of the Muslims who were less aware of their religion than they claimed to be took this position.

Some midwifery experiences, protocols put into practice:

The experience of the booking-in process for pregnant women varied from health area to health area. In some regions it was done by the community midwife than passed on up to the antenatal clinic at the hospital. In others it was done at the hospital and then the file passed back to the community midwife. There was no uniform procedure in either country or in health areas within each country. It seemed to fall to some form of local negotiation.

I was told by a midwife in Scotland that ethnic Pakistani women, at the booking in interview, often or mostly had a translator. When I asked was she sure she said, '...well they will have somebody else with them...', often another female family member or their husband. So the reality was that most women, including ethnic Pakistanis, came to the booking-in interview with a family member, a friend or partner. This midwife perpetuated the notion that translators were always needed, not from specific recalled events, but rather by buying into the language myth. There seems to be a general belief/expectation that 'they don't speak English...' People then marry their recollections to this 'social fact'. Only when asked to reflect and evidence this 'social fact' are they less sure of the 'fact'. I had asked if I could sit in on some booking-in interviews, so I could assess the validity of my theory (that they do speak English). The midwife was quite happy for this, but I would have to check with her line-manager first. The line manager was not willing to allow the observation. By the time the line-manager was replaced with a more 'user friendly' person I had run out of time.

I was told by another midwife at the clinic there would be problems in finding ethnic Pakistanis for me to talk with due the small numbers coming to the antenatal clinic. It was

suggested that the secretaries might select women with '...Asian sounding names...' and let me know when they were booked in. I was told that most of the Muslim women requested female obstetricians, '...although that's not as common as it was...' There are two obstetricians, both female, so there was no problem with fulfilling such a request, should it arise. There was also a change in the system, so only women identified as high-risk, for example '...having medical problems...', come into the clinic. The majority would now be seen by the community midwife teams. One of the things that I found odd in all of these encounters with midwives was they would tell me there were few, if any, ethnic Pakistani women passing through their clinic. Yet they all had strong, if stereotypical, knowledge and views about the ethnic Pakistani population in their theatre. Again this supports my theory of the embodiment of social facts into myths. The acceptance of a language problem begins to enter into the realms of a hyper-reality. There is no first hand evidence or lived experience supporting this 'fact'. The language problem becomes a *simulacrum.*

A midwife working in a small GP practice related that taking case histories at the booking-in interview was sometimes problematic, as often women would tell the interviewer what they thought they wanted to hear – a very similar situation to that often experienced in social science interviews. This was not restricted to Muslims or any particular ethnic group. Quite often in the interviewee's perception it's not relevant or important so they don't volunteer it. Yet from the point of view of the midwife it may be vital. Most midwives said that they found that that happened '...quite a lot...' I was told that the booking-in forms were tedious, but covered all of the information they needed. They were very useful as often they would get sidetracked with other things; it helped them to remain focused.

In the section entitled 'Birth Plan' in which the mother to be is asked to '...think about the following topics[190] and write any preferences in the spaces below...' The midwife told me that Muslims have special requirements for the placenta, which is covered by that section and for care immediately after the birth. Thus they can write 'washing the baby' –

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[190] Birth partner, When to go into hospital, Activity during, Options for coping with labour, Monitoring babies heartbeat, Types of birth, Delivering the placentas, care of Baby immediately following and Going home.

even though it is contrary to current NHS best practice. One improvement, taking into account the above, might be to include some specific mention of '...any traditional or religious requirements...', which would highlight these needs as there may be expectations – on both sides - which may lead to disappointment if these expectations are not fulfilled.

In another region the booking-in form is completed by the community midwife and one GSM that I talked to had to hope that the community midwife had the foresight to make a note of any language issues so that the GSM or midwives in the hospital could have an interpreter present if needed/required. Sometimes, I was told, GSM consultations had had to be cancelled because of this problem. However, my guess would be that the majority of women, certainly from the ethnic Pakistani side would speak English. It may well be shyness or embarrassment with a stranger which is the problem, not lack of English. I discuss this more fully in the final chapter.

One major difference between health regions was whether women were asked at the antenatal clinic whether they were married to cousins. One community midwife that I spoke with replied quite unequivocally: 'Yes, well we ask them if they're *related* in any way to their partner'. I then asked whether she thought that the patients answered this question truthfully. The midwife thought about it and then said:

> '...from my own experience I probably think *most* of them do. There are a *couple* of people that might be a little bit cagey about it. But, to be honest I don't think the Asian [Pakistani] majority see anything wrong with marrying first cousins. So they, they'll quite happily say, "Yes it's my cousin." ...' [this question about relatedness is asked of all women at this clinic, regardless of ethnicity].'

I said that I had read that some Pakistanis were worried that their marriage choice would be looked down upon, perhaps as incest by Health Professionals (Darr & Modell 1988, 188), so they lie to cover any embarrassment. I also told her that I had spoken to a couple, who lived in North Shore, that were first cousins and they had told me that they had

lied to the midwife when asked for exactly that reason. Sharon said: 'Oh, right.' Most of the other midwives did not ask about marriage to close relatives, and even were somewhat taken aback that anyone would see any clinical need to do so. Nor did one of the clinical geneticists I met with, notwithstanding that there was a national screening programme in place.

There were other issues for Muslims, for example shaving the baby's head. I continued the theme by retelling the experience of one particular woman I had spoken to who told me about an ethnic Pakistani mother who had taken her baby into the bath with her, whilst still in hospital after giving birth, to wash him and shave his head. The midwife who found them was very annoyed and snatched the baby from the mother saying, 'You can't do that.' The midwife I was talking with interjected: '*Why not*? It's *her* baby!' I said that it appeared it was a breach of protocol. The story had first been told to me a couple of years previously and perhaps there had been changes in protocol. However, such stories remained current within North Shore as we spoke.

I discussed the practice to put the baby onto the mother's tummy immediately after the birth. She said that was the current practice in Riverside. Similar protocols and justifications were related by this midwife to those I had been told previously. For example, '…the promotion of a lot of skin-to-skin contact for the breast-feeding…' and the reinforcement of the protocol in the audit systems: '…it's on all of baby's care plans… the time that the skin to skin was started or if not started, the reasons why they didn't want it…' This midwife added that there were other protocols coming on-line in a similar vein. For example: '…a lot of hospitals are now going away from washing and bathing babies straight away because they think that it loses their body heat too quickly and so they should be *dressed-up* instead…'.

Sharon, a North Shore midwife, wondered:

'...how that, that goes along with people who, you know, don't want babies next to them immediately. I know there are a lot of women who don't want the babies next to them until they have been washed.' (See also page 128-9).

Here the concern was with all new mothers, not just Muslims or ethnic Pakistanis. Some midwives seem oblivious to race/creed/colour and are interested in mother and baby, others feel hampered by the restrictions put on them by protocols and guidelines which force them to differentiate because of ascribed ethnicity. Whichever is the reality, best practice protocols are potentially institutionally racist in their application.

Genetic Counsellor's narrative and videos – information enacted:

Genetic counselling is problematic, as there are often problems with the patient's retention of the knowledge imparted during the session. Panter-Brick states, when discussing Saudi Arabia, incomplete assimilation of the genetic information is no less common than in the UK (Panter-Brick 1992, 71). There are also many other difficulties involved in genetic counselling. Rapp (1998) discusses some of them. She highlights the diversity of clients who see a genetic counsellor – factors such as variability in social class, ethnicity and education. As with other forms of counselling it is an interaction with the counsellor, who is in this case having to do two specific things. Firstly, assessing the client to pitch the information at the most effective level for the client and answering their questions as they arise. Secondly, having to convey highly technical information in terms that the client can assimilate, whilst being non-judgemental and not leading the client into making decisions they are not happy with (Rapp 1998, 144-46).

I talked with Jade, a GC in Citadel, and asked whether she thought that Pakistanis did not perceive thalassaemia to be a problem that affected them as individuals, which perhaps explains why they often did not present for appointments. She said: 'Yes, yes it is, absolutely, yes that's exactly what it is.' I mentioned that other Health Professionals and some ethnic Pakistanis had suggested that Pakistanis exhibited poor time-keeping with

regard to attendance at appointments. Jade agreed this was often the case and described how she dealt with this problem:

> '...what I do now is I use my cascade screening programme also as an education system. I educate people that actually are *potentially* at risk, not the full population. I send them a booklet, that's easy to read with good pictures in it, to e*verybody* that I know is a carrier. I also send a letter saying, "This is what I would have told you. If you want to see me make an appointment and this is what I am going to talk to you about."
>
> 'What's been happening of late is that people that didn't turn up before, youngsters, come to me when they've got girlfriends. And so it is working – but it's got a sort of "five-year delay" sometimes [laughs].'

Jade told me that there had been education programmes in Cyprus and in Sardinia for many years. For this reason the incidence of thalassaemic births in those countries has diminished. Jade said this was because people there made informed choices. Many of these people were staunch Roman Catholics, abortion is a mortal sin, prohibited, but they made their choice. Many of them would have known of children dying in the family. The grandparents would know of the horrible deaths of children in the families also. So there is, according to Jade, already a community awareness of the disease. Very often that is not the case in the Pakistani population because there was such a high death-rate because of infections and other unknown things. And nobody knew what the children and young adults died of; they were just 'not well'.

Jade told me that babies with thalassaemia major '...become very whimpery, but this was the case also if you have a bad bout of gastroenteritis - and you die.' For this reason thalassaemia is not in the folk-memory in the Pakistani population, so they do not see the risk associated with this disorder. Furthermore, any such folk memory would also be disjointed by the diaspora. The generation now having children almost certainly were born in the UK and see no links to illness in the sending community. Added to this is the firm

belief among Muslims that their death is preordained by Allah, and could not be changed. Even if that were possible one should not attempt to alter Allah's will. Herein lies the problem of effective intervention. To do one thing is a sin (abortion), but not do something (undergo testing in order to have a healthy child) is also a sin. It is how to explain this delicate balance that is the challenge with ethnic Pakistanis.

Often people are seen, by clinicians, not as individual people but as a set of symptoms or an illness to be cured. Jade told me that she got around this problem by making a point, very early in the consultation, of saying: 'Hey, you're a normal person. I am carrying at least 20 mutations also. You know what your mutations are, I don't…' Most of the literature that Jade supplies to her clients is available from the APoGI website.[191] In addition Jade also provides a booklet[192] for each different genetic condition, altered slightly from the APoGI site to better meet the needs of her clients. Jade has prepared a different booklet for each hospital as different hospitals took slightly different approaches. These amended booklets are constructed in consultation with midwives at the various hospitals and are tailored to meet the particular needs and procedures at each different hospital. As she is aware of which obstetrician the '…at risk…' couple will be seeing she is able to construct a custom made booklet that matches the individual hospital and obstetrician that they go back to – '…Everything is tailored to that…'

Jade said that her idea was that the couple are aware of their at-risk status and then as soon as they get pregnant and want choices they get in touch and get it checked up again. They can get a booklet and chose the obstetrician and have all the information to hand. They are then able to say to the obstetrician, this is what we want, this is what we don't want. This is what Jade means by empowering the couple with knowledge. The booklet legitimates their choice and the information empowers and validates their decision with the clinician. To some extent this levelled out the uneven power relationship in the encounter. The couple have their booklet which may be used to legitimate their decisions and demonstrates to the

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[191] http://www.chime.ucl.ac.uk/APoGI/data/html/hb/menu.htm A site operated by University College London, promoting open access to genetic information.
[192] I was given a copy of one such booklet.

obstetrician that they have accurate information on which they have based their choices - they are empowered to say to the obstetrician 'please write our decision in our notes'.

One thing that Jade was certain of in these encounters was that she knew that language was not an issue in attendance at the counselling session. She gave people the option of getting information by sending them a questionnaire and saying you chose not to come or listen but I can give you another date or another time. She said that she was very flexible on that. She said people did not flag [tick] any option on the letter and commented:

> '…So obviously there is not a lot of motivation in the community itself for the service…'

A service she, and others, were offering in answer to a nationally perceived need.

There were several key points that Jade attempted to get over to ethnic Pakistanis. The biggest problem identified by Jade was the ethnic Pakistani side were still not seeing this condition (thalassaemia) as something that had been beneficial to their fore parents and so was not necessarily negative. Secondly, that we are all carriers of something of a recessive condition, but it doesn't do us any harm. And it's very rare that you meet this other person (who carries the same mutation). And thirdly, that they do not really come early enough to see the GC so that they have a chance to make choices. Whatever choices they make is OK with the GC – she says that it is about informed choice not eradication. Jade told me of one family who made a choice not to have prenatal diagnosis and to accept the handicapped children that may come. Jade says that is fine, that it is not an issue, that is a choice. Her main concern was that many people did not have an informed choice. Once they make that choice it is important that they are supported in that choice, whatever that choice is. So the function of a GC is to discuss this choice with them. To make sure knowledge and information are accessible at whatever level of education they have, even though this is often quite difficult.

Thalassaemia videotapes:

Jade played me four of the videotapes that she shows to clients to inform them of the nature of the illness and options available. The first tape was made for GPs to give them more information about the disorder. It was made by the [UK] Thalassaemia Association and is intended especially for the Pakistani population. Most of the next tape was a view of thalassaemia from a mother's perspective. The third tape is called *All You Need to Know About Thalassaemia* and is a public information film. Finally, tape four tells the story of a Cypriot girl who describes just how awful it had been to see her brothers and sisters dying because of the disease, or more specifically by not complying with a regime of chelation therapy.

I began to watch the first videotape, aimed at a GP audience. The first speaker is a South Asian doctor. He is dressed in a suit and sits behind a desk. His accent and mannerisms suggests an 'Oxbridge' education. From the outset there are clear indications that he holds a position of power. He describes thalassaemia as an '…inherited blood condition…' He tells us that: '…a child born with thalassaemia is unable to make enough blood…' We are further informed '… there are two forms we can recognise clinically. The first form is thalassaemia major the other form is thalassaemia minor, which we prefer to call thalassaemia carrier state…'

A new, white, speaker tells us there is a 1:4 chance of thalassaemia major when both parents carry the trait. He then tells us which populations '…people from Asia, people from Cyprus… are going to be…at higher risk…' We are informed that the disease is not so frequent among Northern Europeans. This statement immediately suggests a separation of people by 'race' – and makes no mention of people of Asian genotype-origin that were born in Northern Europe.

A new female speaker, tells us the percentages of the population '…in all the Asian sub-groups…' who carry the gene mutation (carrier state). We are told that in the general population it is around 5%, but in pockets '…in India, Pakistan and Bengal…' it is '…as

high as 15%...' 'So it is numerically a very, very important problem and in England today it is important to remember the number of affected Asian people...' Here we are offered a conflation as a 'scientific' or 'mathematical' certainty. It does not tell us that the numerical importance can be read as between eight-five and ninety-five percent of this population are mutation free, that is not at-risk. The whole sense is that 'these people' [South Asians] are at-risk and as a group should be treated as such.

The second tape that Jade showed me was aimed at a lay audience and was made as part of the Star Project, by the Royal Berkshire Hospital, Reading. The tape takes the form of an interview with a mother, Mrs Khan, who talks about her son Iftikhar (Ifti) who was born 1982 with beta thalassaemia major. The video tells the viewer it has three aims - to provoke dialogue, to influence attitudes and to affect change.

The mother tells us that as there were no outward physical signs of the thalassaemia, Ifti refused to admit he was ill. It was not until the death of one of Ifti's close friends that the realisation that he would have to comply with chelation therapy was brought home to him. We are also told of Iffti's doctor's warning of Ifti's imminent death if he failed to comply with the therapy. Mrs Khan had four children – Ifti was the third child. Up to age three months he was very pale and had diarrhoea a lot. This fits with my findings in Pakistan where people were more concerned with diarrhoea and dehydration than genetics and congenital defects. Ifti was taken into hospital at that time and diagnosed with thalassaemia major. It would be unlikely to have been diagnosed in Pakistan and he would have died without either himself or his family being aware of his genetic condition. It is only when he, and his family, entered a Western health context that the diagnosis is made and appropriate, Western medical interventions are applied. Within the NHS sufferers are able to receive appropriate medical treatment which should offer a much extended life expectancy.

The interviewer then asks if it was at this point that Mrs Khan and her husband realised that Ifti's illness was due to their carrier status. Mrs Khan said that this was so, clearly she felt a sense of guilt for having 'defective' genes – the victim blaming scenario

was clearly being portrayed (cf. Douglas 1986). There was no mention of the positive aspects of the adaptive mutation that Jade said she talked of with her clients. There was a feeling throughout all the videos that children were needlessly born with thalassaemia and an overarching sense that the carriers had an obligation to succumb to the medicalisation and geneticisation process and to atone for their 'sinful' DNA. Also the eradication of the mutation was another common theme of the videotapes.

Mrs Khan tells us that she was '…brought up in this country…' and that she was unaware that she was '…a carrier…' Her tone is subdued and one can sense that she feels real guilt for not having this knowledge (cf. Hallowell 1999). She goes on to tell us that she did not know if her two sons, born before Ifti, were carriers. After Ifti's diagnosis her two sons were checked and found to be carriers of the mutation.

The interviewer then asks how Mrs Khan felt about having any more children after she had been diagnosed? There is a long pause before she answers. She then says 'at this stage I had three boys. My husband wanted to have had a girl so I tried again.' She had to travel to London to be tested whilst she was pregnant. The daughter tested negative for the trait. Mrs Khan became pregnant again, this time the test was positive for thalassaemia major. She told the interviewer: '…It is a very difficult decision to make. We took about two weeks to decide. My husband left it to me to decide…' The distress in her voice was clear as she recollected the process again. Mrs Khan reflected on how painful the treatment was for Ifti, with '…all the needles and things…' Finally she says: '…I, we opted to go for a termination.' The interviewer asks how may weeks pregnant she was at the time of the termination. Mrs Khan replies that she was nearly six months pregnant and described how she had to go through full labour to abort the foetus and how traumatic that experience was. This had the effect of instilling the need for early testing, which offers less traumatic abortions; there is no suggestion that the 'defective' child should be born.

The third videotape, *All You Need to Know About Thalassaemia,* was also made by UKTS and the same doctor as Tape 1 appears again here. 'This video is about thalassaemia,

which can be a very serious illness', we are told by the commentator at the beginning of this video. 'If you originate from Bangladesh, India, Pakistan, [the] Middle East, [or] Mediterranean you could have thalassaemia', the commentator continues in a rather prim voice. We are told there are two forms – major and trait. The voice goes on to tell us about thalassaemia trait, or thalassaemia minor, and about carriers who suffer no ill effects from their mutation. The tape continues by explaining, in accessible terms, if both partners have the trait then there are the 1:4 range of possible outcomes per conception. It begins with the worst case scenario - thalassaemia major – '…which is a very serious blood disorder…'

The voiceover reminds us that if the woman is a carrier then there is a chance that any children may be born with thalassaemia major. Again it is the female that is seen as 'defective' – in fact both partners have to be carriers, not just the woman. The tape reinforces the patriarchal nature of Pakistani society. The voiceover continues by informing us that there is a 'special test', which the woman can take in early pregnancy, to find out if the foetus has thalassaemia – '…even before relatives or friends are informed that she is pregnant. If the baby is confirmed to have thalassaemia major she has the option of discussing termination of the pregnancy.' Again the UKTS are advocating eradication via termination. And again this circumvented any form of counselling or outline of options – one of which is to have the child. Often, for Muslims, this would be the preferred option. This would almost certainly be so for the first child, according to Jade.

The voiceover continues: 'Thalassaemia major is a severe blood disorder.' Here the possible conflation between 'thalassaemia [trait] and thalassaemia major is made in the mind of the viewer. This may cause confusion and lead to one decision being favoured over another. But this skewing will be beneficial to the overall aim of this process as perceived by Health Professionals – the removal of risk. The 'final solution' of this exercise is not the short term 'benefit' of aborting foetuses with thalassaemia major, but rather the 'weeding-

out' of the cause – the thalassaemia trait. If there are no carriers there is no risk. The same argument is put forward within the text on the UKTS website[193].

The voiceover continued by reminding the viewer that thalassaemia: 'is an inherited disorder…' The blame is then put upon the parents (or more specifically the woman, see above) for a condition over which they have no control. There are no lifestyle changes that they can undertake to remove the risk. They are doomed to the very essence of their being – they have 'defective'[194] DNA – a doom that is no more mutable than is original sin.

The video then turns to a father who tells us how draining of time and effort his son's illness is. He describes in graphic detail what is involved in the delivery of the chelation. Again a personal tragedy, but as stated above there are only six hundred cases of thalassaemia major from all ethnic groups[195] in the whole of the UK, and 85-95% of the Pakistani population do not carry the trait. Again the theme offering a worst case scenario is portrayed – again encouraging eradication as the only option.

We are then told that the couple had a 'special pregnancy test' when the woman became pregnant again – '…to check if the baby would have thalassaemia major…' As we are told this we are watching the couple enter the GPs consulting room and sit down. We move to 'live action footage'. The GP says: 'I don't think there is any point in beating about the bush; you know why we are here. We have actually got a conclusive result. I think we have to make a decision. Or confirm your earlier thoughts as to whether you would like to continue the pregnancy or whether you would like to terminate the pregnancy.' The woman says: 'We have decided to have an abortion. We couldn't possibly have another one knowing what he's going through, what we are going through. The scene cuts to a future-time and the mother says: '…And after all that time we tried again [nervous laugh] this time it's [the foetus] perfectly healthy [baby gurgles on queue]'. Again there is only certainty, something Jade says is not possible with any test. Again there is no discussion of options or counselling. The only available option is abortion of the defective foetus.

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[193] http://www.ukts.org/pages/cycle.htm
[194] According to the UKTS
[195] According to UKTS http://ukts.org/

Another father tells us that their third child, a girl, was born with the trait. When she was two years old '… they [the hospital] did a check on her to see if she was suitable, it was a bone marrow transplant. And we got the results back saying she was a perfect match.' The transplant was undertaken successfully. Notably the ethical issues of this procedure were not discussed at any time. Its use of popular appeals that play on fears the parents have regarding their children and the emotional guilt it attempts to generate make this tape very problematic. This was perhaps the most blatantly emotive piece of propaganda that I have ever seen.[196] I was somewhat surprised that Jade used the tape with clients. It seemed to give messages that were diametrically opposed to those suggested by Jade in our conversations.

The supportive and low key style of the tape continues throughout. But the focus moves from positive, relatively unbiased information, clearly presented, to one of options. The message is clearly: thalassaemia equals termination. And family and friends need not be aware of the pregnancy, thus avoiding input/influence from that quarter. This tape was made by the UK Thalassaemia Society, some of whose staff are also sufferers, yet the videotape advocated a move towards eradication of the 'defective' gene. Yet the paradoxes are clear – if that had been the case in the past they may never have been born.

The final tape - *Blood Ties* – tells the story of a young Cypriot woman who has thalassaemia, but has also watched several of her siblings die through non-compliance with chelation therapy. Essentially the children (young adults) decided to let nature take its course and self-select to die prematurely rather than endure the treatment.

Again the biomedical perspective and the ascription of risk tends to describe this genetic mutation in a negative, rather than a positive, light. One of the things I have found to be incongruous in this is that what Jade and her team practice is not the same as that portrayed in the video tape they use with clients. Perhaps my analysis of the videos is more critical as they form part of my evidence. Perhaps the clients are prepared for the videos by Jade or one of her team and thus see only the positive aspects of the videos and are blithely unaware of the negative images portrayed by these tapes.

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[196] As an undergraduate I took a module on Germany 1919-1939.

There is a scene of children playing. The voiceover asks, 'How can the next generation be protected from thalassaemia? (We are shown a little boy playing in a sandpit) For this little boy (Milan) it is already too late. Like other hereditary diseases thalassaemia can be passed to children, unbeknown, by their parents who are healthy carriers themselves'. Again the moral obligation is laid squarely at the door of the parents who must bear the guilt, laid on them by Health Professionals, for having a faulty/defective genome.

There is a pause for the viewer to reflect upon the extremely value laden information given to them up to this point in the presentation, whilst we watch emotive images of children at play. The father tells us, in a remorseful voice, 'We were not aware that both of us were carriers till he was born. There seemed to be some sort of anaemia and the doctors called us in saying we would like to check both of you and subsequently they identified that he was a thalassaemic major. So that was the way we found out as to what the problem of thalassaemia is.'

Throughout the father's input his voice is that of a man who feels great sorrow for his son's illness, which any parent would feel, but there is also a strong feeling that he is ashamed of his genes – he feels he is personally responsible for the illness of his son. He has been made to feel that he should have prevented this risk from becoming a reality. Yet the only way to do that for certain is not to have children (cf. Porter 1997, 640) – the evidence of this comes, on the video, from Dr Marsh: '...screening...can never be one hundred percent...Little Milan is evidence of that...' Again with the negative aspects of the mutation stressed we can see that the biomedical solution is eradication of the adaptive mutation. The father's language also shows signs of medicalisation, for example he frequently uses 'tied' to describe the family in relation to his son's treatment and 'family unit' to describe his family.

Testing and screening:

I asked Jane, a GSM in Jamestown, why she thought genetic tests were done, and, more particularly, who do the tests serve? She explained that the tests were undertaken to

find out whether the foetus and/or the mother are at-risk from either a congenital defect or a life threatening genetic error. She believed that the tests and screening were in the best interests of the patient. I suggest this position is largely based on her training and cultural milieu (both as a white northern European and a Health Professional). The problem, she agreed, stemmed from the constraints put upon all actors by the system. She said that she and her colleagues were just: '...small cogs in a larger machine... ' and as such they are '...not free to act independently...' In other words she and her colleagues just carried out the protocols.

The now subsumed[197] Advisory Committee on Genetic Testing (ACGT) in their consultation document *Prenatal Genetic Testing* made recommendations that all women capable of giving their consent to testing should be able to accept or refuse any or all of the tests offered (HGC 2000, 4). Furthermore, consent should always be obtained for each procedure and each test (HGC 2000: 4). Appropriate support should be given in preparation for and subsequent to genetic testing (HGC 2000, 5). The woman should receive the results of the tests in a form that can easily be accessed and understood – including limitation of accuracy and significance of the results. This should be done by an appropriately qualified professional (HGC 2000, 5). In addition her GP and family, where appropriate, should be provided with information pre and post-test (ibid).

Ashcroft (Hinxton 2003) suggested that some of the basic requirements for valid consent would encompass three main areas: i] *Capacity* (ability to understand, retain and reflect on the nature of the request), ii] *Liberty* (Freedom from undue pressure, inducement or sense of obligation to the researcher), iii] The *information* necessary to make choice. If we take this theory to the consulting room there are clearly areas of concern. I would argue that all three criteria are rarely, if ever, met in relation to *informed consent* in the medical field.

The first of these – *capacity* – is problematic. The patient is given 'all relevant information' by the clinician and is allowed to ask questions, as they require. Yet the

[197] In December 1999 the ACGT was subsumed into the Human Genetics Commission (HGC)

clinician has had many years of education and training to reach the understanding of the issue. The patients are most likely not to have either of these. Thus they are unable to even ask the right question, let alone process the new data supplied. Retention of the knowledge assumes that there are no factors – for example stress - preventing the absorption of a great deal of complex, technical and often confusing data. Essentially the process assumes that communication has been effective – a rare achievement for Homo Sapiens, as history demonstrates all too well. Finally, reflexivity is a skill that needs to be developed and is difficult at the best of times. This is further problematised by the pressures of comprehension and often, quite literally, decisions of life and death.

The second issue is *liberty.* Added to the above points there *is* additional pressure here via a sense of obligation and inducement, all of which militate against any sense of freedom of choice. The most important freedom – the right not to know - has already been violated. The consultation is the outcome of an identification of a 'problem'. The obligation to engage in risk-management strategies is now implicit in the encounter.

This in turn leads to the third of Ashcroft's concerns - the supply of necessary information to the patient. The client/patient needs information to make an informed choice. The social and cultural milieu in which clinician and client/patient operate may often be so different that mediating a set of shared understandings may be difficult, if not impossible. The information is at best subjective and, as previously highlighted, the patient often does not have the where-with-all, whatever their ethnicity, to begin to know what information is necessary, let alone seek that, or additional, information from the clinician. Quite often this information does not offer any cure, other than abortion.

Weatherall states that much is known about the genetic causes of thalassaemia and it is detectable nine weeks post-conception, but there is little else that can be done, with no 'cure' available. Therefore is there any point to prenatal testing? (Wellcome News 20, 10-11) Cystic Fibrosis is another genetically detectable congenital defect. However, the only chance of the baby not being born with the disease is if '… an articulated truck kills the

mother before she gives birth...' (Wilkie 2000, pers com) So we have a situation whereby we can detect defects at the genetic level – but the only 'cure'[198] available is abortion.

It has been suggested that patients are, in some way, coerced into choosing to abort by Health Professionals, wittingly or unwittingly on the part of either side. The literature suggests that one way this may be done is when clinicians refuse to carry out diagnostic tests without prior agreement from the parents to terminate the pregnancy in the event of a positive result. There have also been claims that clinicians have outlined worst case scenarios of the child's prognosis. Both of these outcomes militate against patients making informed choice, in any real sense, and preclude the possibility of informed consent (Anionwu 1993; Atkin et al 1998).

This culturally biased view of what is essentially a physical phenomena lies at the centre of the observed problems of communication between the two sides studied. There is often a perception, by ethnic Pakistanis, that the NHS is in some way trying to stop a long established cultural practice (FCM) and is using science [genetics] to prove their point. I would argue that this view is frequently counterbalanced in the NHS perception that South Asians are not interested in advice, testing or abortion, '...because they are Muslims...' Both of these positions may be true, very occasionally, at an individual level. However, neither was true from my observations as a general rule. The problem lies somewhere between differences in risk perception and failure to communicate – and here I mean technical issues and perceptions of at-risk rather than any inability to use English as a mode of communication.

I had been talking with a clinical geneticist and his GSM when I asked about issues of consent involved in the screening process (NSPFTH). Were the women truly aware of what was being tested for and how ethical was the disclosure of the results of such tests? Blood tests are routinely run on pregnant women, many of whom are unaware of what is being tested for, and the women are often not given the results of those tests. Dr H said: 'Oh absolutely. That's exactly right. So for a whole series of issues...' The GSM interrupted:

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[198] With the possible exception of cells or bone marrow transplant from a suitable donor.

'...The midwives don't take blood without them [pregnant women] knowing! All of the tests are discussed with them.' Dr H countered: '...But the issue is whether they understand what the test is for and that's always been a kinda, is a concern with the serial screening.' Dr H continued by suggesting that population screening was not really necessary, what is needed is screening of people that are in the high risk category. They should then decide if they are going to have blood screening or not. He then queried whether patients then want to opt to have an invasive test such as amniocentesis or CVS. The GSM was none too pleased that the geneticist disagreed with her audited world. This encounter shows the polar opposites of the attitudes I have observed in Health Professionals. There are those who see reflexive discussion to be a constructive activity and others who see any questioning of protocol and auditable procedure as tantamount to heresy.

Amniocentesis is seen, by Health Professionals as being less risky to patient/foetus than CVS. I asked why that was so, for it seemed to the layman (me) that CVS was less invasive and from the description and pictures shown to me it seemed much less of a problem all round. The GSM explained that a finger or a toe may be 'taken' in error during the extraction process of CVS. We discussed the time factors and ensoulment issues for Muslims and the GSM agreed that CVS, even though statistically more risky may be a better option for Pakistanis/Muslims as it can be carried out at an earlier stage of foetal development.

What is the blood test and what happens if it is positive?:

I asked a midwife in the same Cakestone hospital to describe the screening process for the haemoglobinopathies:

'First the woman would be tested, as part of the 'full-bloods' undertaken at the booking-in session. They can not tell just from the woman's blood that there may be a problem of thalassaemia, you then need to check the father's blood. The haematology department then sends a letter inviting the partner to come into the

antenatal clinic to give a blood sample - the midwife sees him and takes the blood…'

The midwife did not know what happened next as there had been no positives in the last few years, in fact she could not ever remember a case in all of the years she had worked there. She said that there were far more South Asian men called back for blood tests than 'white' Northern Europeans. She thought that was because there was a greater risk for South Asians, but was not certain.

Some 'real-life' experiences of the process:

I spoke to one man, an Islamic scholar in a Scottish mosque, who had just gone through the blood test process via his wife's antenatal clinic – the same one that I had visited on several occasions. He told me his wife had been screened at the clinic and she then received a letter telling her that she may have the thalassaemia trait. He told me that his wife was '…a bit shocked….', she was worried what the letter meant. The letter also said that he needed to be screened also. He went to the hospital to have a sample taken as soon as he could. After the sample was given the midwife told him if there was something urgent they would let him know. He said he had not received a phone call or a letter so he hopes he is not a carrier. He said I could have the letter to read to see how it had shocked his wife – but they had taken it from him at the hospital and would not give him it back.

He continued to tell me how distressed his wife had been over the letter. She was worried all day and tried to be brave; the letter seemed to say that the baby could have things (genetic disorder) wrong with it and he told me again that she was shocked by the letter. Apparently the letter said that if there was a problem '…they will sit down with us and tell us everything.' He tried to reassure his wife that all would be well and not to worry. He told me that she kept pestering him to go and give blood to find out for sure. He said if the baby did have something wrong, things happen, it would not be the end of the world.

Ramaz, a waiter working in Cakestone, had been married for eleven years to his wife Zahana and had a son, Ramzul. Ramzul was four years old at the time of the interview.

Zahana had been in the UK for nine years. Ramaz was born in Bradford and Zahana was born in Kashmir. Ramaz and Zahana are first cousins. She is the daughter of Ramaz's father's sister. Ramaz told me of his experiences and interaction with the antenatal clinic at Integerpool.

Zahana had had the standard blood test at the booking-in interview, at Integerpool. On a subsequent visit to the clinic the results of Zahana's tests triggered a request for Ramaz to have his blood tested also. Ramaz explained to me that it was for '...HIV and hepatitis and stuff...' He went on to tell me that he had been '...a bit of a lad... in his younger days... before he got back into the religion...' He said it was '...just to check...' I asked if it was for thalassaemia, as I thought it odd that an antenatal clinic would test the husband for such. He said that it was '...certainly right...' no one had mentioned thalassaemia to either him or his wife. Nor had they asked whether they were relatives.

He did not think his children were at risk of having thalassaemia and nor did he think that marrying a cousin might make the risk, if there was any, any greater. All of his family married with cousins. Not only that but if a child did '...get a thalassaemia...' it would be '...god's will...' and they would cope. I outlined how time consuming taking children to hospital on a regular basis might be. Ramaz replied that there were lots of family to help if the baby was sick.

I made an appointment to meet with one of the midwives at the antenatal clinic where he said he had been tested to find out why he might think he was being tested for HIV/AIDS. The midwife told me that the screening programme was operated jointly between the antenatal clinic and the haematology department. I related that the man believed that he had been tested for HIV/AIDS at the antenatal clinic rather than to ascertain whether he carried thalassaemia trait in his genes. I said that one of her colleagues had said the antenatal clinic never take blood from men to test for HIV/AIDS. The midwife said: 'Yes, we do sometimes.' Her answer was quiet, as if confirming what I was about to report. So this incident remained a mystery, but my guess is that the man was mistaken about the

HIV/AIDS test as such a test would have been highly unusual, and as it was quite recent I suspect that the midwives would have remembered such a deviation from the norm. What it does highlight is that the explanations, although clearly understood by the Health Professionals, are not being understood by the patients or their husbands.

A further indication that Health Professionals are not perhaps getting the message across effectively can be seen in another story told to me by an informant. Samana, a shop owner in North Shore, has five children, three boys and two girls. The youngest girl was eighteen months old at my last visit. The oldest boy carried the thalassaemia trait – which means one or both his parents also has the adaptive mutation. Samana has Hepatitis B, caught from a dirty needle on a trip to Pakistan. The whole family's blood was tested and that is how the son was found to have the trait. My guess is the father was also found to be a carrier, but due to patient confidentiality it was not disclosed to Samana. There was no risk as if only the father carries the mutation the worst-case-scenario is that any children from the union may merely be carriers. But even though they knew the son had the thalassaemia trait the family did not understand what it meant. Language was absolutely not an issue in this case yet the Health Professionals had failed to explain what was meant by 'trait' and what the implications were for future pregnancies and marriages. I did my, by then, usual explanation which both parents understood at the first telling.

I asked a restaurant owner in Judderstone if he was aware of thalassaemia. He said that he had never heard of it and asked me to explain what it was. I gave him the by now standard explanation of the adaptive mutation and the possibility of thalassaemia. He asked how he could find out more about it. I said that a simple blood test was the first step. At this point Jamal rolled up his right sleeve and offered me his arm to extract the blood necessary for the test. I quickly explained that I was an anthropologist and if he was keen to undertake a test he should see his GP. I doubt if any clearer proof of the willingness of this side to act upon information regarding the haemoglobinopathies is needed. I have found that people, once they are aware, are more than willing to do what is suggested by the Health

Professionals in this regard – the proviso is that it is explained in a way that is accessible to them.

> I leave the final word on testing and screening to the GC who said:
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> '...the test is an easy thing to do... But it needs to be accompanied by information. You need to empower people. It's no good being paternalistic about this – you need to empower people... I want my parents to go away feeling good about themselves, not *faulty*, not *wrong*.'

The National Screening Programme for the Haemoglobinopathies (NSPFTH):

I should have suspected when I was told so many times that 'we don't see many' that the risks from thalassaemia were low. I had been led on by writers like Weatherall (1998), Ahmad (1994) and Bittles (1998) et al and the setting up of the NSPFTH. I had begun to suspect that my impression formed from the literature and conferences were at odds with the reality. However, it was not until I spoke to an eminent haematologist that my suspicions were finally confirmed. The reason 'we don't see many' is that there '*aren't* many' to see. However, one clinical geneticist I talked with suggested that '...due to the high rate of consanguinity within this group...' there would be a different spectrum of genetic disorders than in the Caucasian population. The aim of this subsection is to elucidate why the screening programme is implemented.

The haematologist at Integerpool Hospital told me that the screening for the haemoglobinopathies had been a long established strategy in the area, on his initiative. However, the neonatal element of the national screening programme was not taken up in his area. This suggests that the national programme is something of a pick-n-mix allowing individuals to 'do their own thing' – in other words it is personality led. The haematologist saw no benefit in population screening and asked what other practitioners I had talked to were doing. He seemed happy that his opinion was borne out by the current practice in other regions also. We discussed other issues and he regretted that his health region had not yet put in place any genetic counsellors, he and the obstetrician had to do the job.

I had been told that haematologists were reluctant to share patients with thalassaemia with the geneticists. A manager of an antenatal clinic, in a Scottish health region, asked me: 'Do you know why? [Laughs]' I said I had been told that it was to do with professional boundaries and areas of expertise being jealously guarded. Her comment, on hearing my stories, was:

> [mock exasperated sigh] 'The arrogance of some people. [Laughs] ...as midwives we used to have to request that they [haematology] would check for thalassaemia... I was told last year[199] that even if you forget to put it down the [haematology] labs will pick this up *anyway*...'

I took from this that the national programme was in place, but the Health Professionals who operationalised it were unaware of its name. But she said that these pathways were perhaps not hard and fast. Women might have a family member who had had a baby that had a haemoglobinopathy. That might be a genetics referral because her GP might refer it through the genetics pathway. So it is possible for either route to be taken.

I was told by a midwife, in Riverside, that she left London and went to work, for a short while in Lungton, before moving to her present job in North Shore. She said that they undertook no haemoglobinopathy screening at all in Lungton. There were few South Asian families living in the area but when she asked colleagues about how the haemoglobinopathy screening was done, they asked what that was. I asked the same midwife whether the NSPFTH exists on the ground in North Shore? Her answer was a quite unequivocal: 'No'. She continued by telling me that it seemed to vary from hospital trust to hospital trust. This again suggests that the national programme is patchy in its application and I found that very often I gave as much information to these people as they gave me on many occasions.

I spoke with Dr K, a clinical geneticist who was in the process of opening an office in a Riverside hospital to deal with the haemoglobinopathy situation in the area. Previously he had travelled down from Oldfort when necessary. The midwife I spoke to was not aware

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[199] This fits with the introduction of the National Screening Programme for the Haemoglobinopathies in April 2002.

of who he was or what his responsibility might be in regard to her work as a community midwife. I had asked a local GP, in 1999, what procedures were in place for dealing with any cases of thalassaemia. He thought '…someone came down from Oldfort…' but he was not certain. I was somewhat surprised at his response as I know several of his patients had the trait and also a little boy who had major, according to his mother.

Most of what I observed was driven by motivated individual Health Professionals rather than by a UK wide screening programme. Health Professionals that I spoke to told me that this had been their experience also. It was individuals with an interest in the haemoglobinopathies who were responsible for undertaking appropriate screening and support. Certainly it was not a uniform national programme.

Several senior Health Professionals were concerned that the NSPFTH was something of a sledgehammer to crack a walnut. There are many other more urgent genetic disorders, affecting greater populations, which were not being tested for. There are other conditions that are just as common, for example haemochromatosis in the Northern European population. One in seven of us are carriers, yet few, if any, of the 'white' Northern European population have had a bowel test. Few even know what haemochromatosis is. Also there is Cystic Fibrosis (CF) for which the testing of all the newborn babies was started recently - 1:20 of us are carriers of this mutation. So it is quite clear that the NSPFTH is somewhat anomalous. This supports my contention that its main function is to tick the government's ethnic minority box. An eminent Scottish haematologist quoted less than 5% of the Pakistani population were likely to be carrying the thalassaemia trait.

There is then a national screening programme in place, to detect the haemoglobinopathies, with only six hundred cases of thalassaemia major, from all ethnicities, in the whole of the UK. The problem of '…gallons of blood…' being needed for transfusions that Dr J had spoken of did not seem to be an issue in the UK. So the '…public health issue…' that Dr T had spoken of was not that significant in strictly numerical terms. The issue of alpha thalassaemia is not a public health issue, although it was clearly a

personal tragedy for the parents[200]. Dr T said that the national programme was in place to ensure no one was disadvantaged. I asked what specifically were we talking about. He said the government's aim was to ensure equal access to health for all. I then asked if the purpose of NSPFTH was a tick in the ethnicity box, with regard to health care? Dr T agreed that that was the case, just part of the overarching audit culture that now pervaded most [if not all] of life in the UK. The screening programme for the haemoglobinopathies is based on the government being '…seen to be doing…' rather than on clinical need. There is a need for information and education for the wider ethnic Pakistani side, with testing and support [by trained genetic counsellors] on hand for individuals and their families, rather than population screening programmes that are perhaps seen as paternalistic and not understood by the population being screened. Moreover, as the programme is essentially only targeting minority ethnic ('black') sections of the population, I argue that it clearly falls within McPherson's definition of institutional racism.

The NSPFTH is, in many ways, much the same as the national programme set up to eradicate the problems associated with the mutation of Chromosome 21 – Down's syndrome. Wheatley (2003) argues that:

> '… [the tests] place intolerable pressure on mothers – to risk their babies' lives for knowledge that they may not even be able to deal with…'

The tests that Wheatley is talking about are CVS and amniocentesis, the same tests which are used to divine thalassaemia. I have talked about the procedures and the risks elsewhere in this thesis. Wheatley writes:

> '…I had doubts about the wisdom of this test; the last one had resulted in the unnecessary termination of a healthy pregnancy. I did not want to risk it again; I wanted to trust the baby, growing inside me, to be alright. I found I resented the burden of responsibility being placed on me and my husband – to choose or reject the dubious gift of knowledge. What would we do with it anyway? The

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[200] Alpha thalassaemia causes spontaneous miscarriage in the third trimester.

> implication of such tests is that there may be a decision to be made. If the result is positive, you are offered the Godlike choice to end a life…
>
> …I was prey, as all women have been for the past fifteen or twenty years, to the burden of choice; the responsibility to avail oneself – or not - of proffered technology, the right to manipulate nature to one's advantage.'
>
> (Wheatley 2003, 4)

Wheatley is clearly biased in her position; she lost a healthy foetus after each of the tests. However, the arguments she makes are valid and fit within the current debate on prenatal testing. She wrote:

> '…I'm doubtful about the advantages of all this prior knowledge, this talk of statistics and percentages and risk. It makes us craven and fearful.'
>
> (Wheatley 2003, 4).

The writer suggests that for some women faith is enough to see them through and refuse the test. Also some women would not undergo a termination, even if the test were positive, so why take the test? However, she rightly states that most people now accept a culture that demands protection from risk and demands perfection. For this reason, she says, most couples would find it difficult to ignore the obligation - not to opt for the tests offered by modern medicine.

The next generation of mothers are to be offered an increasing battery of genetic tests on their unborn children. They will have to listen to the doctor or midwife outlining implications and outlining potential risk – information Wheatley worries '…they won't know what the hell to do with' (ibid). This scenario is no different for any prospective parent – regardless of their ethnicity or religion. I have argued that choice is desirable and people should have that choice. I do not envy either the clinicians or their patients in having to deal with increasing options and invasive tests as more and more options to achieve perfection come on-line and are made almost mandatory by politicians who set national screening programmes in place seemingly with increasing rapidity.

Thalassaemia enacted:

When I talked with one woman and her husband they said that they had been told of the risks with regard to thalassaemia for their children. However, they had not fully understood what a 1:4 risk was in real terms for their children. The woman told me that she understood that if she had one child born with thalassaemia then there was no risk for the next three pregnancies. That is that only one baby in four would be poorly – the next three would be healthy. I explained that when both partners are carriers the risk was one in four - for every pregnancy. That is every pregnancy had a 1:4 risk of the baby being 'sickly'. After some discussion she said that she understood. Her husband then asked why the doctor had not explained the risks to them. I suggested that the doctor had told them, but perhaps had not checked that they had fully understood. We talked of how they (and almost every Pakistani I have met) did not like to say 'no' or to suggest that someone was wrong - particularly if that person was perceived to be of a higher social status than they. They both agreed that it would be bad manners to say 'no' or suggest that the doctor or midwife had not explained it well enough. I suspect that the doctor explained the risk – as he understood it – and the couple agreed that they understood – as they understood it – and the communication process had not taken account of the cultural differences that had informed each actor's understanding and perception of the risk.

Another mother did not perceive thalassaemia as a major problem. She says that she has been told that her child will just have to '…take some tablets…', (to remove the excess iron from the children's blood, after transfusion one imagines). The little boy's heart problems are seen as a much more significant worry for the family. The genetic issues are not visible nor are they within the experience of her family or friends. A further factor that was felt to be significant, by the Health Professionals, was the late age of conception (29 years old). Shakeila envisages the defects as a result of '…weakening of the blood…' She told me this is also how she and her family understand genetics. Her husband, Rizwan, was told at the mosque that the Prophet (PBUH) had said that too close marriage weakened the

blood and that it should be avoided. But it was felt that it was fine to marry first cousins, because '...it was tradition...' and also '...there have never been any problems before...' This again feeds into the GC theory of no race memory within this population. Also his family cited evidence that the Prophet (PBUH) did not forbid FCM, just said that '...you shouldn't do it too much...' There is no sense, within Rizwan's family, of what 'too much' would be, only that his family did not do it 'too much...' What a psychologist might describe as cognitive dissonance.

Shakeila[201] had had offers, from Pakistan, for her daughter's hand in marriage from close relatives there. She has turned all of them down on genetic grounds. I asked if she would be happy to arrange a marriage from within the *biradari* for her daughter. Shakeila said most emphatically 'No'. I then asked if, with hindsight, she would still marry her husband. Shakeila had told me previously that her marriage had been arranged, and that she had fallen in love with her husband after they were married. However, her swift and emphatic reply of 'No' came as something of a surprise. In line with expectation I had imagined that her reply would have been upon the lines *qismat* and that she loved her husband and the children were 'gifts from Allah' - blessings. However, Shakeila said: '...the health of her children came first...' If she had known about thalassaemia or any other congenital birth defects she would not have married her first cousin.

The boy's thalassaemia was discovered during routine blood work in preparation for his heart surgery, at nine weeks old. Then the hospital did a full family history to determine the likely effects of the thalassaemia, according to Shakeila. It was discovered that the thalassaemia trait was common among her husband's family. As Shakeila was his first cousin, and the children both had thalassaemia, it is certain that it ran through her family also - although she blamed her husband and his family for the illness in her children. She said that this disease was traced back to a sister/brother marriage in Pakistan several generations ago. Health Professionals had cited this incestuous relationship as the cause of the thalassaemia in her two children, according to Shakeila's description of events. She told

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[201] Her son had multiple congenital defects, linked, according to the hospital, to her first cousin marriage.

me that the hospital had '...six thick files...' on her and her family. I asked if anyone had mentioned genetic testing or genetic counselling whilst she was pregnant. Shakeila said that nothing had been mentioned then or since.

Another young mother, Kay, said that she had had no [genetic] tests done before she married her first cousin. She was of the opinion that most people, if they had a disabled or poorly child, would just say: '...it was just bad luck...' However, in keeping with others spoken to who had lost a child her perspective was a little different regarding her subsequent pregnancies and existing children. She told me that she will either have tests done for her daughter before choosing a partner for her, if a cousin is chosen, or allow her to '...marry out of the family...' if she wanted to.

The woman had a baby boy, who died after six weeks. He was, according to her description: '...'flat' when he was born...'[202] The baby was also a breach birth (unlooked for). Kay said that the doctors initially said they could find nothing wrong with the child. However, the Health Professionals later began to suggest to the couple that the problem with the baby was because of their '...first cousin marriage...' This theory was further supported, for the medical staff, when her niece came to visit her whilst she was still in hospital. She had some sort of disorder which '...shortened her muscles...', causing her to limp and to have to be aided by walking sticks.[203] The midwives asked her what relation she was to the visitor. When she said that it was her niece the Health Professionals told her that this was the final 'proof' that it was genetic factors that were directly responsible for her child's 'flatness'. Having been shown pictures of the effects of untreated beta thalassaemia by a GC it is entirely possible that the niece was suffering from the bone deformation associated with this condition.

After the child died a post-mortem was undertaken. The woman said that there were no signs found which indicated that the death had been attributable to genetic factors. It was,

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[202] Very much the description given by Jade the genetic counsellor, at City Hospital (Citadel) when describing the symptoms of a thalassaemic child.
[203] Again this fits with the pictures and descriptions give by Jade (GC at City Hospital) regarding the affects of thalassaemia.

according to Kay, '...the fact that the spine was crushed by the midwives who used the forceps during the delivery that did the damage...' I have no way of knowing or checking the validity of this story. It may suggest that Health Professionals had again being suggesting that FCM was a pivotal factor in assessing a clinical outcome among ethnic Pakistanis, on Riverside. This story is very similar to that of the sister/brother union that was blamed for thalassaemic births in another family of ethnic Pakistanis in North Shore described above. However, it could equally indicate some sort of cognitive dissonance on the part of the families involved. As I was unable to talk to the Health Professionals involved or access medical notes, I have no evidence to support either scenario.

Whether or not the baby's death was attributable to congenital birth defects or poor delivery methods the woman believed it to be her husband's fault. His '...bad blood...' had made the baby sick. She believed the Health Professional analysis that the illness was due to FCM. She says that she accused her husband for all of the six weeks it took the baby to die. She believed that a congenital birth defect, because he was a first cousin, had made her baby sick. This was supported by the medical evidence from Health Professionals in the maternity ward. Here is yet another case where 'bad blood' is seen to be the cause of the illness/death of an infant. There was no genetic counselling in either case, if the informants are to be believed. Note, in this case again, no blame is apportioned to the mother or her family – even though the recessive nature of the mutation, and the way that it is carried within this side, means that the mother and her family must carry equal genetic responsibility for the birth outcome.

This woman said that it was a major decision for her and her husband to decide whether to have more children. The doctors, according to her, had strongly advised against further pregnancies. If true, this supports the contention that the problem was in some way genetic and that FCM may have been a significant factor in the poor birth outcome. However, the couple went ahead, after talking with the Imam, with further pregnancies, and now have three children to show for their decision. The woman told me that all three are

healthy. She also said that if she had followed the 'wisdom' of the medical profession she would not have her children. This story, shared as it has been in the area, will do nothing to develop any interest within this side in discovering the nature, if any, of the potential congenital defects within their gene pool.

Another woman said that she had seen singers and actors, on Zee TV, discussing genetics and the risks involved in marriage between first cousins. She also said that the younger generation are using the advertisements to tell their parents that they don't want to marry their cousins – '…see, it says so on the telly…' For this reason she thinks that more information, perhaps on a video, would be a good idea for future generations.

I met one woman, a member of a wealthy and thus influential family, whilst I was still a lecturer and we had a general discussion of genetic information and consanguineous arranged marriage among the South Asian (mainly Muslim, Pakistani) population of Riverside. Rose (not her 'true' name, but the one she had registered at the college with) said that: '…Allah pre-ordains children and thus illness/birth defects…' Yet, she argued that there are no children with birth defects in, what she described as, the Mirpuri community in Riverside. Rose said that any such defects are sent by Allah '…as a test… Allah never gives you a burden that is too great to bear…' For these reasons Rose said that there was no need for genetic counselling to be provided in Riverside. It is this culturally driven attitude, held by a gatekeeper between the ethnic Pakistani population and the state, that perhaps makes access and discussion of the subject so much more difficult.

Attitudes to thalassaemia are mixed, as we have seen. I outline one further perspective here. I asked Kim, whose father was born in Pakistan and whose mother is white, if she had heard of thalassaemia and if so would she take it into consideration when selecting a marriage partner. Kim, after some thought, replied:

> '*Well*, I didn't really know about it before so I never even considered it. It wouldn't bother me. If I did have the test if it was to help anything, in any way, then obviously it's a positive.'

I described the 1:4 risk and the blood test for thalassaemia and how it was part of the routine full-blood tests done on all pregnant women in the UK. I asked whether, in the scenario I described of thalassaemia major, Kim would consider a termination. Kim answered:

> '*Probably not*, because if I'd wanted a child [and] if he or she was going to be a carrier of it. If I'm a carrier or the guy that I've met is a carrier then fair enough it's going to carry on through the generations but then it's just like anything else like people who are born with other disabilities. I wouldn't terminate just for the fact that they could be a carrier or anything, I don't see any problem with it.'

As I was framing the next question Kim volunteered: 'I mean that's nothing, my sister has just, about two years ago, had a child with it [thalassaemia]'. I then asked if Kim would consider pre-implantation testing she replied: 'No. no I don't *believe* in all that. It's just natural to have what you're *given*'.

This woman told me that her father believed she was a Muslim – '...he told me he had whispered the prayer in my ear just after I was born...', but she does not pray and had read more of the bible, at school, than the *Qur'an*. Regarding ethnicity she is troubled by equal opportunities forms which do not have a space that she feels fits her sense of her own ethnicity. Yet she holds views on many cultural practices that are indistinguishable from those held by devout Muslims (cf. Shaw 2000a, 86-7).

Iatrogenesis and eradication:

I have included a document (Appendix 3) taken from the UK Thalassaemia Society (UKTS) website. The reason for the inclusion of this particular document is that it supports my contention that the UKTS is pro-eradication and is arguably overly influencing individuals to terminate their pregnancies without proper counselling or knowledge of the other options available. Perhaps I have no right to make these comments as I do not suffer from thalassaemia and many workers for the UKTS do – if the team picture and the videos

produced by UKTS are to be believed.[204] However, I believe along with my informants, that life changing decisions should only be made when all the available alternatives are known.

The document is little more than a polemic against an adaptive mutation. In paragraph three the 'moral blackmail' begins. We are told that families not only have to deal with a new country but:

> '...also with the medical, emotional and spiritual problems associated with the birth of a thalassaemic child...'

The document notes that had the child been born with either major or intermedia, in the 'old country'[205] they would almost certainly die at an early age, which would solve the problem. It would be unclear what had killed the baby and the death would not be too surprising with infant mortality so high. In the UK medical intervention is available, free of charge. All options are available, including letting nature take its course (as is demonstrated in the videos). For me, this document is also disturbing for another reason. It presumes that South Asians are all foreigners, not British. This not only shows ignorance but arguably has racist overtones.

The writer asks: 'Why do I still see thalassaemic children being born.' As if this was a surprise. The writer answers in paragraph seven. Only approximately five percent of the Pakistani population carries the adaptive mutation. The document clearly cites the mutation to be a bad thing. The final two paragraphs continue the emotional guilt theme of the document. It tells the reader that, 'thalassaemia in the majority of cases is incurable, but is preventable...' - again suggesting either abortion of the foetus or eradication of the adaptive mutation from the genome. Finally, the writer tells us that our parents were ignorant and uneducated. That was their excuse for breeding 'defective' children – that is, children in whom the adaptive mutation is present. The readers are evidently forced to agree with the writer's assertion that eradication is the only option – else liken themselves to their 'uneducated' parents. Again the text suggests to the reader the very limited options of

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[204] The personnel featured in both sources are in many cases the same.
[205] Though I would argue that 'new' and 'old' are both Britain for the vast majority.

abortion and eradication. For ethnic Pakistani Muslims this may well be problematic. More so if this site is their first contact then they may well be put off further investigation and thus be put at-risk by the very organisation that one suspects was set up to help them.

Oddly on the same UKTS website there is a speech given by an ethnic Pakistani[206] who has thalassaemia major. In his speech he describes his treatment and its impact on both his and his family's life, 'warts-and-all'. Yet this text is positive and advocates education and informed discussion, not eradication. He says, not unsurprisingly, he would prefer not to have thalassaemia major but with the help of friends and family he lives life to the full. Thus the two sides of the debate are given on the UKTS website, but eradication continues to be the main theme when the evidence of the videos, which are used in this education[207] process, are considered.

I attended a lecture given by Robert Winston (2003), the geneticist, at St Andrews. The lecture concluded with a slide of a young boy. Winston posed the question about this boy and the illness that he was suffering from. I guessed that it was thalassaemia, I was right. Winston's key point was that if we eradicate the adaptive gene which causes thalassaemia and then climate changes (due to global warming) again make North Africa and the Mediterranean an ideal environment for the mosquito, many millions might die in infancy since the population will have lost the natural protection against the malaria vector afforded by the thalassaemia gene.

Winston brought this argument into sharp focus using the allegory of the Breughel woodcut *The Alchemist*[208] (Appendix 6). Winston described the picture as if it were a contemporary research facility and also a portal to a possible future. The Alchemist instructs his wife and assistants to slavishly follow technology without consideration of the next generation. Thus their endeavours are valueless, because of their short-sightedness, and leave them demoralised (one might argue alienation is relevant here also).

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[206] Speech given at Asian Awareness Campaign Launch at the House of Commons on 22/1/1998, almost the same time as I began my research. http://www.ukts.org/pages/persona2.htm
[207] Tapes viewed at Yorkhill Glasgow and supplied by Margaretha van Mourik.
[208] Breughel's woodcut '*The Alchemist*' (Original in the Kunst Museum, in Berlin)

The window, in the top right of the picture, shows the future. The children (abandoned by their parents due to their focus on the research) are sent to the poorhouse in the future-scape. Winston argued that we show little concern for future generations with current genetic research which had unknown outcomes for future generations. I had originally planned to use the example of the Geoff Goldblum character in the film *Jurassic Park* who stated that scientists (cloning dinosaurs from DNA retrieved from bloodsucking insects preserved in amber) were: '…too busy seeking if they *could*, to worry about whether they *should*…'. I believe that Winston's allegory is a much more elegant description of what is occurring in the genetic world today.

Alchemists are oft identified in the popular mind with attempts to transmute base metals into gold. Breughel's *Alchemist* was originally seen as an allegory for this futile activity (Gibson 1977, 56-7[209]). The Geneticist's attempt to rid the human genome of unwanted mutations is seen by Winston (2003), and I think with good cause, in much the same light. The activities of the group in Breughel's *Alchemist* are directed by the alchemist who reads from an open book. He points to the words 'Alghe-mist', a pun on 'alchemist' and *al-ghemist*, Flemish for 'all is lost'. As Winston has argued, once an adaptive mutation, for example thalassaemia, is eradicated from the genome all may well be lost, in two ways. Firstly, the gene mutation, which took perhaps a million years to become widespread, will be irrevocably deleted. Secondly, as maintained already, without this mutation many millions may be lost to malaria in the future.

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[209] Gibson, W.S. (1977) *Bruegel* (London: Thames & Hudson)

CHAPTER ELEVEN

THE LANGUAGE MYTH DISPELLED

Is there a problem with language?:

My strongest argument in support of my claim that there is a language myth is that I have researched this thesis entirely in English. The myth's claim, that ethnic Pakistanis in the UK commonly have trouble speaking English, is refuted by the fact that if this were so my research could not have been done. I tried to lean Urdu using the BBC [Shaw's] language course *Getting by in Hindi and Urdu* (Shaw 1989) and I eventually tracked down and bought *Colloquial Panjabi* (Bhardwaj 1995) - all to no avail. To learn a language you have to speak it with others – you have to hear it and think in it. In all of which I failed miserably. Why was this? Essentially, everyone from the ethnic Pakistani, and for that matter ethnic South Asian, sides spoke English. What little Urdu I did learn has gone – I never needed to use it. All I can still say is *Assalam alakam* and *Valakam salaam* - both of which I assume are Arabic. My conclusions about the language myth do not, I think, come from a personal ineptitude in language acquisition, or from sheer chance in choice of informants. Perhaps I should recall an event way back in 1998 when the following bizarre conversation took place.

I first met Mrs Begum, a corner shop owner, with Salina in 1998. I had been told that she spoke very little English – typical for the older generation if we are to believe the language myth. The most striking event of that day – and I think the basis for my argument of the language myth - was related to the actual process of translation. As we talked – with Salina translating totally for us both – I wondered how Mrs Begum had conducted business in North Shore with little or no command of English for so many years. The interview started quite normally – I asked a question in English; Salina translated my question; Mrs Begum answered; Salina translated Mrs Begum's answer into English. So far, so good – standard operating procedure. Then I realised that I was talking to Mrs Begum, in English,

and Mrs Begum was answering me in English. Again nothing out of the ordinary. I have found in many experiences in this and other localities that as the informant became more relaxed English became the norm. What was unusual was that I had been told that Mrs Begum '...spoke very little English...'. Perhaps Salina had been mistaken? But what was even more unusual – and I argue vital for my argument – was that Salina continued to 'translate' for us both, happily 'translating' the English into English for a large part of the interview. I would ask Mrs Begum a question in English, Salina then translated it for Mrs Begum in English. Then 'translated' Mrs Begum's English answer into English for me. Salina acted as a 'language conduit' and continued to translate, English into English for the question; then English into English for Mrs Begum's reply. All in all a very surreal - but formative - experience.

What was most interesting, particularly as the NHS uses the same system, is that Salina was flavouring the translation for cultural context for both parties. Some answers were slightly modified to make them more culturally relevant for either Mrs Begum or me. Salina did not realise what she was doing throughout the process. No harm was done, but it did begin my thinking about language and translation which became an important issue in this research. Firstly, many (if not most) South Asian women of childbearing age speak fluent English, and therefore need no translation – but many Health Professionals say they use translators. Secondly, the translation given may not be accurate. It may be culturallyflavoured to meet the expectations of those who are being translated for (Health Professional and patient), or, more sinisterly, most of what is said is not passed on, for whatever reason. This situation clearly gives much power to the translator, who may well be a family member - in the cases I have looked at, the husband. I return to these issues below.

Salina in her translations would give a sense of what had been said or asked rather than a verbatim translation. There were also times when Salina made little additions which reflected her knowledge systems and background. Salina has described what she does when translating as much like a stenographer or audio typist. The words go in her ear in one

language and come out, without her thinking, from her mouth in another. She speaks five or six languages and, along with most South Asians I have met, can use them all in virtually one sentence to convey complex meanings and ideas – often taking the most appropriate word in each context, to convey the ideas. For me, this single event highlighted language as more than just a problem. It became a vital part of my analysis of the interaction and communication between the two sides studied.

Health Professionals say that they do not have time to practise treating minority ethnic groups '...like everyone else...' For the same reason I believe that Health Professionals assume the language myth to be a reality. The self-fulfilling prophecy is that everyone says there is a 'problem' with language. Unfortunately, much academic work also perpetuates the myth, especially that done within stringent time and budgetary constraints, common to much research carried out in contemporary Britain. As I was writing up this part I was sent the final report of the *Nisaa Project*[210] (2003) which echoes inaccurate statements about 'children being taken out of school to translate' (Green: 2003, 153) or women getting by using sign language and broken English (ibid). I am most disappointed in this document for two reasons. The first is it is written about people that I have met, and I am certain it does not reflect their reality. The second is that one of the co-authors knows this – she worked with me on my research in the very early days. I suggest this document is merely another tome in the gatekeeper wall. In the same post I received another document, which was cited in Green, which states that 70.5% of the (ethnic Pakistani) population said they feel comfortable...' speaking English at the doctors, in shops or using public transport (Hills et al: 2001, 5).[211] This figure rises to 90.6% for the 14-24 years age set. One notes that the fact that some people feel 'uncomfortable' in speaking English in social situations is far from proof that they are incapable of speaking English in social situations. I will now describe my experiences of language during my research.

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[210] A research project with the aim of empowering BME (Black and minority ethnic) women in Ironopolis. Funded from the SRB.

[211] I had been banned from reading this report by one of its authors (a former supervisor) and it took me some three years to finally acquire a copy.

A conversation with Bilal, a 'wide-boy' from Jamestown:

I have talked about the problems of access after the September Events and I adopted desperate measures to enter the field in Scotland. Below is a short excerpt from one of those attempts.

Here is an extract from a conversation that took place outside a fruiterers' on the main street of a small town in Central Scotland, as I tried to make contact with the ethnic Pakistani side:

Me: 'Hi, does your father own the shop?'

Bilal: 'Why do you think he is my dad?! Is it because of the colour of me skin?!'

Me: 'Yes. My name is Richard Murphy. I'm an anthropologist and I'm doing a PhD at St Andrews. I want to work with people from the Pakistani community in Scotland.

Bilal: 'I'm Bangladeshi!!'

(At this point the other male [Bilal's cousin] interjects: 'I'm Pakistani...')

Me: 'I need to do some interviews with people from the Pakistani community about cousin marriages'

Bilal: 'How much does it pay?'

Me: Nothing, I'm a student and don't have any money.'

Bilal: 'Oh, well it was worth a try... OK I'll talk to you, but I don't have time now. I'll give you me mobi number and you can phone me, if y like pal.'

If it was not for the subject of the questions and I did not identify the ethnicity of the participants there would be no reason to suspect that my conversation had not been with two Scottish youths. The essence of my argument is that the truth of the matter is *I did* have a conversation with two Scottish youths – only skin pigmentation identified them to me as potential informants.

Ethnic Pakistanis:

On my first visit to the Standaira the community workers, when questioned by me, made their replies via Salina. She was their Line-Manager and I got the sense that they

expected her to take the lead in the interaction with the 'outsider'. She had introduced me to them, yet I got the sense that they did not want to give too much away. However, as the interview progressed, and the atmosphere became more relaxed, they began to look at me when they answered. In future meetings with the women, either in pairs or individuals or with others, this relaxed mode continued. It was yet another example of the family/'outsider' relationship with ethnic Pakistanis - once I had been introduced and vouched for access was permitted. Throughout this conversation English was the only language spoken. However,

Kalsoom, who owned a corner shop in North Shore, talked to me directly, in English, from the start of the project, rather than through Salina. My guess was that she speaks with 'white' people all day, every day when she works in her shop. Also Salina had introduced her to me as '...an unofficial community development worker...' who filled forms in for local residents and dealt with the state on people's behalf, if they had problems. She was widely known in North Shore (and in Hills et al: 2001) as 'Sarah'. She was more North Shore than South Asian in her world view.

Tazneem, who I met when she was giving a paper at a conference at the University of Durham,[212] told me how the men had acquired the English language through the workplace. When they were joined by their women folk and younger children they communicated for the women. This was their way of controlling their women in an alien, and often hostile, landscape. The exception came when their children went to school and learned English also. These children then interpreted for their relatives (mainly female). These children then went on to do degrees – education became a status symbol among ethnic Pakistanis. The women, over time, became fluent in English also.

One such woman was Kausar who came to England after marriage, about ten years ago. When Kausar became more confident, during our first meeting, she began to speak directly to me; her English was, at that time, not very good.[213] Razwan, her husband, also spoke good English and did so throughout the first interview and all those that followed.

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[212] And subsequently when she taught the Urdu class that I attended.
[213] Although it was far superior to my Urdu/Panjabi.

However, Salina persistently led them to return to speaking Punjabi, not intentionally I think. But Salina is a gatekeeper and a link to the 'white' majority ethnic state and by her actions she [and many, many others] perpetuate the myth that language is at best an issue and at worst a problem in communication between this side and the state apparatus[214].

In another interview in 1999 I was introduced to Mohamed and his wife Samina, again by Salina. Mohamed's wife Samina made little contribution in the early stages of the discussion. She either kept quiet or only spoke when directly spoken to or in a side conversation with Salina. (She behaved like a 'good' Muslim wife). However, she did take more of a role as time went on. At first she spoke only in Panjabi, to either clarify points that Mohamed had made or to make her views known. As it became clear to her that Mohamed was not passing on her comments [nor was Salina translating them] Samina began to make her contributions and comments on Mohamed's remarks in English. The main debate centred on the rural/urban dichotomy. In the main they argued about differing lifestyles followed, and views held, by rural and urban dwellers – the essence of the argument was: rural = backward, urban = modern. But Samina said that people still had healthy babies in Pakistan, what happened was the '...Will of Allah...' and '...if you were meant to have a healthy kid you would get one wherever you lived...' This last comment was 'pure' Riverside, a clear indicator that communication in English was not an issue for this woman. Nor were conversations with Mohamed's sister whom I met shortly afterwards. Jo spoke to me in English [she was born in the UK] in all our conversations.

Another woman who was very much a 'Riverside Lass' was Shabnam. She was very much a product of her environment in Riverside. The other interesting point from this encounter was that it was the first interview that I conducted entirely in English. Even the interaction with Salina was in English. Shabnam was very sure of her views on cultural issues that affected her life. She blamed the problems that women suffer, in Riverside, on '...*jahil* thinking...' by the men. Shabnam explained *jahil* thinking as being old fashioned, uneducated 'rural' thinking. A more accurate translation of the word *jahil* would be,

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[214] See Green: 2003.

ignorant [of Islam] (Eickelman & Piscatori 1996, 12). Shabnam added: '…that's men who fall back on the *Qur'an* to justify what they say…' Shabnam swore almost constantly during our conversations and her style of speech was in keeping with her working class North Shore milieu.

As a general rule I have found that many of the working class people of South Asian origin I have met speak at least one South Asian (Punjabi/Urdu) language and are happy to intermix four or five languages within any one conversation. Yet the more 'academic' the family the less likely they are to be fluent in a South Asian language, some do not speak any language but English – the medical students for example. There is a desire to teach young girls from the working class Urdu as this imparts social status on both the girl and her family. As I have said elsewhere, education is much prized within this group. However, many middle-class South Asians neither speak nor read in any other language than English in the conducting of their daily lives.

It has been said that the older generation, born and raised in the South Asian subcontinent, has difficulty in speaking English. I disagree. When I first visited a large mosque in Scotland there was some discussion (in Punjabi), by the old men, of who I was and why I was there. After which all of the men talked in English and indicated that they were interested in my research and would help me in any way that they could. Once again communication, in English, was not a problem – even with this random group of old men.[215] As we all sat around on cushions talking, a *Qur'an* in English, was produced from the library shelves that covered one wall of the room. Later in the day volumes of the *Hadith*, all written in English, were taken down from the shelves to evidence specific points being made. As the 'congregation' of the mosque were mainly South Asian, texts in English would seem to be an extravagance should I be mistaken about the almost ubiquitous use of English by this side. This strongly reinforces my argument that suppositions that translation is required are not only problematic in the economic sense it is also proof of institutional

[215] My guess would be they were in their late sixties or older.

racism. This also has very serious implications regarding risk as communication issues may well obscure genuine interaction between the two sides.

When I spent time in the mosque in Cakestone the men were told, by Abdul, to speak only English in my presence. No one objected; Abdul was a 'big man' within the mosque but equally nobody was unable to comply with the 'request'. And we talked about complex issues of ethics, morals, genetics and interpretation of the *Qur'an* among many other issues that interested me regarding my research. Interestingly, the sessions delivered at the mosque by a group of Muslims travelling the country encouraging men to become 'better Muslims' were all delivered in Panjabi and there were 'real-time translations'[216] offered in other parts of the hall. There were many young ethnic Pakistanis in my group (Panjabi/English) who were unable to understand the speaker as their first language was English (Scots to be more accurate). Also later in the evening I was put to work helping prepare the meal to be served after the final prayers. Again English was the most common language spoken during these preparations.

A multi-ethnic view of translation:

I have used this subheading as the commentators are English, Scottish and Dutch and are talking about translation into South Asian languages by the NHS.

I asked two young ethnic Pakistani medical students their perceptions and opinions in regard to my research. Tasmin said:

> 'I think it will be quite useful. I think that like the more we can know about this sort of thing the better, because people are having problems explaining to nurses and doctors about certain things. They just can't do it or there are certain related medical issues for example childbirth or whatever. I think they [Health Professionals] should be aware of it. I think there are so many Pakistanis now in Britain that we're not, we're not a minority anymore…'

I returned to the issue of the NHS and 'special treatment' for Pakistani/Muslim patients with a young male ethnic Pakistani medical student. I was particularly interested in

[216] Panjabi/Arabic in one corner and Panjabi/English in the other.

whether he saw any mileage in the NHS translating all of its leaflets into Punjabi or Urdu. He said:

> 'Actually yes, I think there is, I mean even today they [the NHS] are doing it. Like, for example, you go to Bradford or Glasgow you got the hospitals, you'll see signs like in the Urdu.
>
> 'I think like for example people who have been here for thirty or forty years like for example my father, he came here in 1962, and his English is a bit bad. I know his friends who, their English is not too brilliant.
>
> 'They would prefer to read in Urdu or Punjabi or whatever. And err I think it will be a useful thing in that sense.
>
> 'But as in, I don't think it would be necessary may be like twenty or thirty years down the road. Because like people will understand English, like as generations go by people brought up and educated in this country.'

A mixture of the two standard replies here. He tells us that people who have lived and worked in the UK for '…thirty or forty years…' cannot function in English. He also says that language is not an issue for those born and educated in the UK. I began to unpick his statement firstly about his father and his friends' inability to speak English. I suggested that need for translation was often to cover embarrassment rather than any lack of English. He further commented:

> 'To an extent yes, I would say so. I think you're right. People can communicate, you know, Pakistanis like. People like my father my grandfather my father's friends – they can communicate in English. But like you say it could be like they're just shy.
>
> 'Out in the supermarket or they're at the bus stop or they, for example, if I'm in the bus station I might sit and have a chat with someone [a stranger in the queue], while I'm waiting [for] the bus. But they probably would not do that, just

because they're sh[y] embarrassed of how their English sounds. I would have to agree with you there.'

So translation is not the issue, shyness is – though this is not borne out by Hills et al (2001) nor Maan (1992) who tell how the South Asian side is well assimilated into the Scottish landscape.

I asked Freda, the midwife in North Shore, if the interpreters used by the doctors in the surgery were professionals. She said:

'I think it's just somebody from the community. Not their community it's, a group. The only reason I know, cos last week we tried to get an interpreter for an asylum seeker. We do have difficulty getting them at the times that are convenient to everybody, you know, for us to get to see them, for the family and everything. We find it very difficult to get interpreters.

Again, there is the conflation between '…their [Pakistani] community…' and an 'asylum seeker'. Health Professionals seem often to lump all 'ethnics' into one problematic [Pakistani] group in their minds-eye. Again, I see this as evidence of the problematic aspects of audit culture rather than any racism in individual Health Professionals.

I think the most cogent support for my argument came in a comment made by a GC in Scotland who said that:

'…many young people have come to me; in Citadel for instance, are fourth generation [laughs] Asian people. They get really upset because I offer them a translator or somebody from their own community and they said "Wa hang on man we tend to speak better English than you do!" And they do because I've an excellent [accent]…'

Health Professional view on language:

The CCRI Asian Survey, carried out in 1982, states that most Pakistanis in Riverside spoke Punjabi, and this group were also least likely to speak English well. The survey also reported

that this impacted on, and caused problems for, some individuals when visiting their GP. I suggest that generational issues are present here, as is the case with the Alexander Report[217]. Significantly the Asian Survey[218] (1982) reported that the older generation were also least likely to be able to read their own language – this remains the case today (RCVDA: 2003). This inability to read their 'own' [South Asian] language(s) suggests that much that has been done, with regard to health education literature, has been wasted. This puts grave doubts on whether informed consent can be given in any real sense. Current practice may well meet 'ticky-box' quality assurance targets, the patient having been informed in writing and at the 'appropriate' level, but one can hardly see this, in any real sense, as being truly *informing* to the patient of their condition.

I asked Health Professionals about the Chinese or the Serbs or the Croats or any other minority ethnic group? A manager in an antenatal clinic in Scotland said, 'We really have to try it [translation] for everybody…' I said that it would be an almost impossible task given the likely ethnic diversity of every conceivable user of the NHS – there are many, many languages, dialects and customs - any of which may present at the next antenatal clinic. I said that it was my contention that this very attempt at equal access was at the root of institutional racism within the NHS. Jo asked me: 'What would you do instead then?' I said I didn't know, at which she laughed. I continued by saying that both our experiences had demonstrated, at least among the South Asians, that language was not really a problem – most (if not all) of the women we had met spoke very good English. The problem came from the context in which that communication took place, either via stereotyping or by constructing ethnic minorities as if they were alien to this country.

She agreed that language, in most cases, was not an issue here. The women could understand English without any problem. I told of the strange 'translation' that had taken place in Mrs Begum's shop in Riverside - which she found highly amusing. This was

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[217] I also would surmise that the CCRI research was undertaken almost certainly via gatekeepers and thus may well reflect, if my experiences during this research are any yard-stick, the vested interests of a politicised cultural elite.

[218] A comprehensive research project carried out by CCRI into all aspects of South Asian life, in Riverside.

particularly pertinent to my argument as the translator was on the NHS panel for Riverside. This brought into question the value of such schemes for the majority of people who either have lived in the UK for perhaps nearly half a century or were born and educated in the UK. I also pointed out that, based on the evidence in Riverside, all of the information is passed through a 'cultural filter' at least three and perhaps more times in a single conversation. The manager said: 'Yeah, I think it's bound to be'.

I asked how they split the husband or the mother-in-law away from the pregnant woman and speak to her directly. The manager said:

> 'That's right. That's kind of where we're coming from, trying to - we kind of get off with it in maternity but you tend to have to have conversations with the lady, on her own, in the toilet or something. Somewhere where he's not going to be able to follow her, you know [Laughs].'

I suggested that perhaps the men were not deliberately trying to keep their partner's in ignorance. She said:

> 'Not always, some of them are protective or it's just cultural – that's the way they do it.'

I said I found that once people got to know me there was no problem in communicating. She agreed. I also said that by Health Professionals there is often a perception that 'these people' are 'Muslims' or 'South Asians' or 'ethnic Pakistanis' rather than individuals who live in the UK. This sense of the 'other' seemed to be significant in looking at this communication 'problem'. People noted the appearance of the 'other', and reacted accordingly. The manager also agreed with this. I continued by saying that all of the Health Professionals I had met were positive in their views about minority ethnic patients, but all followed the accepted knowledge and did not have time to question its validity. I suggested that this acceptance of other's description of the 'other' was in some ways part of the problem, not the solution. The manager commented:

> 'That positive can actually be a negative in its own sense. It's only natural.'

The tone of her voice at this point suggested she was assimilating new knowledge, that is to say reflecting on an alternative perspective of the issues being discussed.

I found that very often Health Professionals tended to conflate all 'foreigners' who had problems speaking English into one group. I suspect most of the 'Pakistanis' that I was told about were not ethnic Pakistanis but migrants from other countries, who had problems with communication in English. Several times, when I have asked for clarification, it became clear that the 'Pakistanis' were in fact asylum seekers or other foreign nationals. This may well fit with the stories related by Livia, a postgraduate I met whilst attending a conference at the University of Hull. Livia told us that she had observed two young girls walking through Trafalgar Square dressed in *shalwãr-qamis*. From their language it was clear, to her, that they were Romany Gypsies; they had dressed as 'Pakistanis' as they feared racist attacks if they were perceived as asylum seekers (Livia Jaroka pers. com). This conflation of various minority ethnic groups could skew the perceptions of Health Professionals with the institutional racism that this implies.

I spoke at length with a GSM about booking-in procedures carried out before the mum-to-be came to the clinic and she said that she hoped that the midwife would make a note of any language difficulties so that the midwives in the antenatal clinic could have an interpreter present if needed/required. Quite often this was not done. I asked if this was perhaps because the women might be comfortable with the community midwife and thus feel free to speak English. Whereas shyness might become a factor when communicating with the midwives at the hospital – often strangers to these women. So there would be no language problem from the community midwife's perspective. Also there was a greater chance that the husband would be present at the session at the hospital as the likelihood is that it will be out of town, as is the current fashion for the larger hospitals. There may be a (cultural) pressure to let the man do the talking and the most effective way of ensuring this is for the woman to claim that she is unable to speak English. The GSM thought about this and said on reflection this might well be the case with ethnic Pakistani patients. She had noticed

that when the women were on their own, say for an examination or for a blood sample being taken, they seemed more able to communicate in English.

The GSM also expressed a concern that a translation of what she says to the mum-to-be might be problematic. If the interpreter is a family member, most likely the husband, they may not either have the language and/or the education to pass on the message accurately. This presupposes that the will is there to offer an accurate and unbiased interpretation of the information. Often there would be a lengthy and complex explanation, which often lasted for some minutes. Yet the interpretation would take scant seconds. There was a feeling that not all the complex information had been conveyed. Furthermore, many of the terms and concepts for genetics are conveyed in English - much of which can not be accurately translated. However, if I am right then the mum-to-be will have understood all that was said. The translation may well consist of a private discussion, between partners, of the information.

Another possibility, again social, is that the ethnic Pakistani may be too well mannered to point out to the Health Professional that they were fully able to follow the process as being described in English. Added to this there is a shyness, or perhaps a reticence, to engage with someone from outside their own sphere. All patients are involved, despite protocols to the contrary, in an unequal power relationship in interactions with Health Professionals and all of us are, to some extent, wary of strangers.

I suggest that levels of education might be a more significant factor than ethnic origin in the conveying of the complex information relating to genetics. Communication needs to be set at a level that the patient can comprehend. Thus any discussion has to take into account education, or lack of it, as well as ethnicity. There is some debate among Health Professionals whether there would be a need to teach everyone a medical and technical vocabulary so that Health Professionals could give lay patients information and allow for an acceptable level of understanding. One midwife said:

'No, I think you've got to adapt it so *they* understand it, so that you get all the information over that you want, in a way that *they* can understand it. There's no point talking at the same level for everybody. Because there are then people who will just go out of here and won't understand a word that you've said, it literally gone straight over the top.[219] So I think you need to get that information over to *them*, but you've got to do it in a way that *they understand*.'

There were clear parallels to be drawn here with the experiences of the GC who admitted getting it wrong sometimes and it being a continuous learning process. There are also implications for Health Professionals who make snap judgements as to ethnicity and educational background. There is evidence below of the pitfalls that can ensue from such processes.

Often those snap decisions are mistaken. In Scotland one midwife told me how she found that the language problem that she had initially perceived was inaccurate:

'...We invariably found out that the women could speak, or certainly could understand more than *we* thought they could. Their understanding was there, and even their speech was often better than we had appreciated but we didn't know that until we got to the postnatal period and one day *there was nobody else around* and they spoke to us.'

I commented that I had had exactly same experience in Riverside, though not so much in Scotland. I suggested that many of my informants self-selected not to speak English, for whatever reason that might be[220]. The midwife said:

'I think so, its "self-select". [Pause]...it's a concern we have... it can also be seen as a potential control mechanism. There's always the man or sometimes it's the mother-in-law that's present, all the information goes through from us to the

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[219] Gestures with flattened hand in a backwards motion over her head. Indicating that the information has gone over the person's head.

[220] Shy or they felt their level of English was poor. Therefore they felt embarrassed or that it was inappropriate to speak because of cultural/religious constraints, and not speaking English was a good excuse without being rude or ill-mannered.

woman. That kind of thing – so I don't know if it's self-select or if it's circumstantially selected [nervous laugh].'

Again further proof that the barrier of language, upon reflection, is not as the Health Professionals have believed it to be. Another midwife told of similar experiences. That is that the women speak English perfectly well but do not do so with a stranger. I have noticed that people claim not to speak English at a first or even second meeting, but suddenly are able to speak English – when they are more comfortable and thus more relaxed. This scenario has been commented upon by almost all of the Health Professionals I have spoken to. In sum, there are barriers, but often they are occluded behind the language myth. A clinical geneticist commented that, '…I have never had a translator; usually there are some people that understand…' Ethnic Pakistani patients he had see had all been able to understand the genetic information being passed to them. The geneticist often has to pass on quite complex genetic information as most of his face-to-face work is with multifactoral genetic disorders.

Young Muslim ethnic Pakistani perspectives:

As Anastasia was studying languages at the university and had visited Pakistan when she was younger I asked about her ability to speak any of the South Asian languages. Anastasia said:

'I couldn't speak the language. So everyone was teasing me.'

I then asked Anastasia if she could speak any South Asian languages now. She replied:

'No, not at all. I tried to start learning but, when I was younger, I got this book out of the library [Probably Shaw's text] "One, two, three, four…" *"It's just too hard now*. You have to acquire the tongue and everything like that. I can't do it.'[221]

[221] This made me feel a little better about my failure to acquire the language – if a person who had a Pakistani father and was doing languages at degree level found it impossible I now see I had little chance of acquiring the language at a sufficient depth. This also strongly supports my argument regarding the NHS attempt at translation also.

Anastasia continued,

> 'When I go down to my aunties, usually every Saturday…they treat me as a daughter… they've got the Asian television on and I just kind of sit there - quite bored, but I do it for them. Dad comes down and the males start talking and I just sit there.'

I then asked if, with her linguist's ear, she could not pick up the language. Anastasia replied:

> 'I can get the gist of the conversation some how, I don't know how. [Laughs] But I know a few words, but like when I'm there they've got the *Zee-TV*[222] …they watch all these soaps and I get the gist of them but obviously with the pictures as well and there are words that are familiar to me but when I seem to say them they sound stupid to me [laughs] because I've never spoken them. But everyone is surprised that I don't speak Dad's language.'

Again Anastasia sees Panjabi and Urdu as her Dad's language' not hers. Also 'everyone' would include Health Professionals.

I asked whether she thought that it was right to expect people of her generation, who are born and bred in the UK, to speak Urdu or Punjabi. Furthermore, did she feel that she was stereotyped as 'Pakistani' by others, in particular Health Professionals? Anastasia said: 'Yeah, I agree, people do have expectations…'

She asked me if I knew how Asians speak English; then answered herself: 'THEY SHOUT DON'T THEY…' She explained that it was just intonation of voice, '…that's how they [Asians] speak…' She continued by telling me how her uncle spoke and how the Health Professionals thought he was shouting at them, when he was not intentionally shouting at them – just talking in a loud voice. So the Health Professionals '...get all up-tight, because they've got this Asian guy just shouting at them…' So quite often, I was told, they do not want to deal with him. She told me that once an Asian doctor came in and said, 'Look yeah, my Dad's like this as well that's obviously how we are. You've got to realise that.'

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[222] Asian language satellite channel.

Anastasia's father thinks she is a Muslim but she thinks not. Anastasia said: 'I don't consider myself to be a Muslim… I don't speak the language.' Clearly Anastasia makes linkages between 'Pakistani', 'Muslim' and 'language' - Islam has ethnic connotations, and is part of 'their' world, not hers.

A final piece of evidence which supports my contention that practices of translation makes wrong assumptions about ethnic minorities is the advertising campaign being run in Scotland by Talk Scotland and funded by the Scottish Executive.[223] A young woman tells us of the confusion that she feels when asked, on forms, for her ethnic origin[224]. She tells us that her felt identity is a Scottish Muslim. Her religion is her most important identifier and as she was born in Scotland she feels Scottish. Clearly offering this young Scottish woman a translator would be not only insulting but also an unnecessary cost on the NHS. The Scottish Executive has got the point – perhaps it is time that the NHS and the rest of the state apparatus caught up. There is little doubt that the surveys, commissioned by the Executive, that looked at, and found, racism in Scotland are the main drivers for this initiative.

Nevertheless, the Executive are moving toward a position which recognises the change in UK society. It is hoped that academia, and thus the wider state that it informs, will soon discover this self-evident truth as well

Anastasia mentioned this very dilemma, eighteen months before the advertising campaign. It came about during a discussion around how she perceived herself – who was she? I suggested possible labels: British Asian, English, Pakistani, ethnic Pakistani, British. Anastasia said:

> 'Yeah, I was laughing at this the other day because…you know…how they've [the university] put all our documents on-line now? …and you've got to amend them… I was looking at what I had classed myself as and I'd just put "Other" [Laughs]. …there was nothing, [pause] like I'd class myself as [pause] 'white

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[223] In response to the plethora of reports confirming xenophobia to be rife in Scotland.
[224] Appendix 2

> Asian' or whatever, like a mixed, there's nothing really like that so I just put myself as *"Other"*.'

Here is yet another example of how the state wants to ascribe difference where the person themselves sees none. The ubiquitous equal opportunities form attempts to audit individuals and categorise them into boxes to allow the construction of false boundaries to meet the needs of target setting and meet criteria for funding bodies or performance targets. Again making work where none existed before. Putting people at-risk often where no risk is perceived. A further example of how Anastasia sees herself to be different from those the state would lump her with can be seen here when talking about cooking at home:

> 'I can't even touch that, they call it the tower – I don't know what they call it in *their* language – it's too hot. I burn my fingers.'

Clearly this particular ethnic Pakistani does not see herself as 'other' – despite what we want to ascribe her as. This, or similar, was repeated many times in conversations I had with people from this side. They are as British as I am, but because of phenotype they are treated in a different manner to the rest of 'us'.

> I asked another young woman how she perceived herself. She began by saying: 'I think firstly I'm a Muslim. I think above anything else I know that. But I would say I was more Scottish than Pakistani. Probably, because my Mum was born in Citadel and although my Dad's from over there I still don't really see myself as being that Pakistani. Although I do see that I'm 'Pakistani,' but probably I'm Scottish.'

Clearly her self perception and that ascribed by others is at odds. I then asked two other ethnic Pakistani women if they were both multi-lingual. They both giggled and said 'Yes.' But after a slight pause, 'Well not really'.

I suggested to a variety of informants, both Health Professionals and ethnic Pakistanis, that it was likely the NHS staff often had to make snap judgements on patients mostly based upon first impressions. I used the example of the two female medical students – they were

both wearing *shalwar-qamis* and had skin pigmentation commensurate with their Pakistani origin. However, that did not take into account the reality of the situation. They had agreed that that was often the case. The first student had said:

> '...if I'm with my Mam...when we, she opens her mouth and they [the 'white' person] realise she is speaking English and she's brought up here and has got a Scottish accent and they kind of take a step back and think "Right, Ok".
>
> I do think sometimes I feel that people maybe do think that "Oh maybe they're not going to understand what we're saying". But when my mam speaks or when I speak they understand'.

So there is often a sense or an expectation that because someone looks 'Pakistani' they are not going to understand what is said to them or they are foreigners or they will not be able to speak English, perhaps they are uneducated or a little slow. This was certainly how a group of young ethnic Pakistanis I met in Riverside thought they were viewed.

The main thread which ran through their narrative was communication, or rather lack of it. Rashid said that a couple of times he had felt that doctors had '...talked down to him...' The others chimed in with comments like '...they sometimes treat you like you're stupid or sumat...' or '...they think none of us can speak English...' or '...we're not educated and stuff like that...' There was also a strong sense that in general most of the people they knew from the ethnic Pakistani side felt much the same way - although not necessarily with reference to 'white' Health Professionals. Some of the most damming comments with regard to communication were about South Asian doctors, both GPs and 'consultants'[225] in hospitals. I was told on many occasions of one particular South Asian doctor in North Shore, from both ethnic Pakistanis and the general population, who was very dismissive of his patients. Also, as noted above, both direct and indirect racism was common within the NHS in Riverside, according to one ethnic Pakistani GP.

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[225] They said consultants but I think they were meaning hospital doctors in general. I attempted to get clarification from the men but the somewhat ironic reply I got was: '...'they all look the same...'

So the younger generation see themselves as Muslim and/or Scottish or English – but the state ascribes them as Pakistani and the NHS protocols prescribe how they should be treated – as minority ethnics. This is not how the individual Health Professionals I have spoken with want to do it, it is the way the feel they have to do it otherwise they face sanctions from above – they are at-risk.

Language – Myth and truth in the early twenty-first century:

If the idea of translation was to give equal access to health then translators should be supplied for all ethnic groups - which would be cost-prohibitive. Furthermore, I suggest that most often the reality is that translation is unnecessary and often seen as insulting. One midwife commented that it was not feasible to have a translator for every patient from the numerous minority ethnic groups now resident in Riverside[226] - 'You can't always meet the need'. This suggested that she perceived a need, but not the economic wherewithal to meet that need. There was something of an anomaly with this informant. The area covered by her patch[227] included at least two of my informants, both ethnic Pakistanis, both had given birth in the recent past.[228] Both spoke good English. Yet this midwife continued to tell me that: i) she was aware of very few 'Pakistani births'; and ii) there was often a need to arrange a translator for this 'community'. There were almost certainly quite a few births within this particular ethnic Pakistani population[229] – so I am unsure what conclusions to draw. My guess is protocol, lack of time and the language myth conspiring to give rogue data. I spoke to both women, in English, and comment elsewhere that their standard was much higher during my return visit in 2003.

Whilst watching the Gaelic language news programme *Eoropa* (25/03/2004, BBC 2 Scotland) there was a segment looking at language within the South Asian population of Glasgow. One of the community leaders informed the reporter that English was spoken in

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[226] An area of great ethnic diversity from the middle of the nineteenth century (Riverside's industrial past formed the very cradle of the British Industrial Revolution at that time) to the present day with large numbers of asylum seekers living in the area.
[227] In this instance she covered both GP practices in the town.
[228] One only days before my arrival.
[229] Two women that I knew had given birth very recently in North Shore.

80% of ethnic Pakistanis homes in Scotland. This is born out by my observations in both Scotland and Riverside, the more so as my research continued through time. The community leader said that his 'community' was now into its third or fourth generation and the majority of them were youngsters, who were educated in the UK and their first language was English. Only the older generation continued to speak the South Asian languages in the home. A third year medical student, also interviewed by the reporter, said she could speak '…just enough [Urdu/Panjabi] to get by….' with members of the older generation. Both the student and the community leader agreed that the current generation do not speak any other South Asian languages well enough to pass on to the next generation.

Alexander (1999) claimed that only '…24% of Pakistanis feel English is their first language' (Alexander: 1999, 22). How do we understand this in relation to the above and the 90.6% of 14-24 year olds who are comfortable in speaking English in North Shore (Hills et al 2001) – an area that the ethnic Pakistani inhabitants perceive as one of the most traditional in the UK. My conclusion is simple – Alexander et al are perpetuating a language myth.

I think the essence of what I am arguing is that having an accent, however strong that accent might be, is not an indication of an inability to speak or communicate in English. Were that the case the NHS would need to employ interpreters for Geordies[230] or the other Glaswegians, to name but two. What I have found is that many Health Professionals assume a strong accent to be an inability to speak English – when the speaker has a high *melanin* level. Ethnic Pakistanis, for their part, and here I am talking about the older generations, were too embarrassed when Health Professionals claimed not to be able to understand them, because of their accent. So, to save any embarrassment, on either side, they use an 'interpreter' to speak for them. When I say 'interpreter' I am meaning someone with less of a 'South Asian' accent. The growth in advocacy projects is a clear indication, and evidence, of this argument. Would Health Professionals think, or dare, to ask a Glaswegian if they wanted an interpreter or someone from 'their community' to sit in? I think not, they would

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[230] There are several texts, languages courses and I believe a dictionary for this. I am also aware of a university course in Klingon – an alien language from a science fiction universe.

ask the patient to speak a little slower whilst apologising for *their* inability to communicate adequately with the patient. But what has become best practice is to call for an interpreter as a first option – an audit solution to a simple problem. A 'solution' that causes embarrassment, offence and alienation of a significant number of British citizens.

CONCLUSION

The research has been ongoing for some five years and I have spoken with many people from among ethnic Pakistanis and Health Professionals, in two quite separate geographic areas. Both ethnic Pakistanis and Health Professionals initially seemed to be homogenous. However, upon closer inspection this was far from the case. For example, there are very marked differences between the Scottish and English experiences for ethnic Pakistanis in Britain. In Scotland ethnic Pakistanis remain culturally diverse and yet are relatively well integrated into the wider Scottish society. Most of the people I talked to in Scotland, when asked 'Who do *they* think they are?', most frequently replied they are Muslims (this is true on both sides of the border). Yet even when that is taken as a given ethnic Pakistanis of the younger generations living 'north-o-the-border' see themselves as Scottish rather than Pakistani. The same can be said of the youngest generation in England, who see themselves as English, but the older generations often wish to maintain their identity as Pakistanis. I attribute that feeling to the alienation that is generated by the rise in Islamophobia, which is so much more prevalent in England. Most of the ethnic Pakistanis I met in England do not feel a part of the wider society. I also see this difference as being very much down to the positioning of gatekeepers between the tight-knit ethnic Pakistani localities and the ethnic majority which has been the tradition in England for many years. In Scotland the ethnic Pakistani population has had a tradition of being more dispersed around the country and in many ways feels less isolated. There are also signs, in both areas, that Werbner's (1990) doublerootedness is becoming a much less potent descriptor for the younger generation, particularly in regard to language spoken.

The Health Professionals were defined by professional persona; my research did not require me to investigate their personal social values. Their role was defined by training and organisation culture. In this sense there was little difference among the Health Professionals that I worked with. Some individuals were more helpful and amenable to entering into discussion than were others. But they all have reached qualification to appropriate national

standard and therefore they were very much the same wherever they worked. The issues that they found problematic were most often common to the NHS rather than individual health regions or countries. This became most clear when I spoke to the medical students at the start of their enculturation process. The attitudes and mind-sets that they exhibited, in our conversations, were very much in line with those of the qualified professionals that I encountered. Clearly their tutors were preparing them to work ostensibly for the NHS in the UK and thus their views and positionings reflected that process. My guess is that had they not done so they would not be continuing in the process. I am in no way saying that these individuals are unthinking automata, but I am saying that protocols and guidelines are effective tools in the development of conformity – to the extent, I would argue, that they are almost hegemonic in their potency.

Among Health Professionals there were different and diverse interpretations relating to the application of national initiatives within different health theatres. A key observation is that the most effective examples of patient care were driven by individual practitioners' interests and not by national edict. Thus I found no two groups of Health Professionals to have the same procedures for dealing with the haemoglobinopathies. I have no doubt that the guidelines were met and that all pregnant women were tested for the potential mutation, via the booking-in procedure, and all followed protocol according to the results obtained. The differences were in the motivation of individuals and in the organisation structures in place to support and counsel patients about the implications of such results.

In Riverside the NHS procedures and protocols relating to thalassaemia were not particularly well defined or well known by the Health Professionals that performed them. It seemed that the specialists in this area were somewhat hazy on what they were doing, or going to do. Several Health Professionals, for example the GPs and midwives, were unaware of the procedures. The system often seemed to rely on chance and a very real sense of *inshallah* on the part of the clinicians. When I did find a Health Professional who was taking positive action, by habitually screening South Asian mums-to-be, this was done on their own

initiative based on experience and interest acquired and developed in previous posts, outside of Riverside. This was in marked contrast to what was happening in one health district in Central Scotland. Training had been given to specialist teams and a stratagem is in place to take into account the very long lead-time between education initiatives and couples taking advantage of the services on offer. In another area of Central Scotland the more effective bits of what is now NSPFTH had been in operation for fifteen years. However, this group were also aware of the shortcomings in their practice due to not having a genetic counsellor as part of the team.

Ethnic Pakistani's awareness of thalassaemia very often seemed to be largely informed by either their contact with me or by their own later discussions following contact with me. For example, a community development worker told me that until contact with me she was unaware of the adaptive mutation. After that, there seemed to be talk of it '…everywhere…'

Risk has run through this thesis as a red thread in an attempt both to link the narratives of the informants and to argue that at-risk status is not solely linked to genetic mutation within a minority ethnic population in Britain. Risk is a reality for all informants, on both sides of the health care divide. In my research, risk has been seen in many forms, both real and imagined. This ranges from the claim, by some clinicians, that ethnic Pakistanis in the UK were at-risk from illness caused by an adaptive mutation of their genome and a cultural preference for FCM to Health Professionals feeling at-risk of sanctions for failing to apply protocols that implied difference with respect to a group of British patients, to future generations of the human race being put at-risk by attempts, in the present, to eradicate an adaptive mutation from the genome via programmes of genetic screening during pregnancy, without true informed consent. But by far the greatest risk I identify is the perpetuation of the language myth within contemporary British society. This risk, promulgated via audit culture, which in turn has led to the perpetuation of institutional racism within the NHS and the wider British state, is central to my argument.

I have argued that the language myth is most often perpetuated by gatekeepers and academics – often via what Wright (1998) has called the 'politicisation of culture'. This has, in turn, led to policy makers and Health Professionals being wrong-footed in dealing effectively with a significant minority of British citizens. These gatekeepers have a vested interest in keeping the language myth alive – it allows them to maintain the power and control they have in their areas - often big fish in small ponds. In addition the state has ticked the equal access box and has been 'seen to be doing', although, I suggest, this is not quite the same as doing. In the vast majority of cases this myth perpetuation has been supported with the best of intentions – but as we know the road to hell is paved with good intentions.

The status quo offers a simple solution to a complex 'problem' – by 'problem' I mean the 'black as 'problem' supposition. A self-fulfilling and self-perpetuating prophecy is at the heart of my argument. With the status quo in place everyone [who matters/has a voice] is happy – ignorance [in regard to the 'other'] is bliss. The state and the gatekeepers continue their dance, but the players in the real-world are left feeling alienated and are ultimately disenfranchised. I have been told, many times, by ethnic Pakistani informants, that all they want is '…to be treated the same…' The sense I have from my informants in the professions allied to health, is that they want to '…treat people equally…' but are prevented from doing so by protocols that force them to treat minority ethnic groups differently – that is to say based on phenotype and accent rather than personal cultural preference or need. All I am suggesting, in this thesis, is that the state review the facts and move away from perpetuating this false divide by its insistence on translation as the solution in the effective delivery of health care. The language myth must be dispelled if any progress is to be made in granting the heartfelt wish of these two British sides. Audit culture is putting both sides at-risk and genetics has often been used as the tool to justify this. Until the state (in all its manifestations) does accept this self-evident truth it will continue to

perpetuate institutional racism which in turn will continue to disenfranchise a significant minority of the UK population, merely on the grounds of skin pigmentation.

In 80% of South Asian homes in Britain English is the language spoken 'around the kitchen table.' Even over the time of this research I have noticed that English has become the norm in households that had been previously multi-lingual. The children speak English at school and continue to do so at home. Thus their parents are *forced* to follow suit. This is of course also evidenced, in no small way, by the fact that I have been able to research this thesis.

As I have argued above, in the majority of instances, accent and audit have been the route cause of a failure to communicate between the two sides. Health Professionals take a too easy audit solution by offering interpreters to people with strong accents and high melanin levels in their skin. I say 'easy' not to suggest lazy or uncaring attitudes on behalf of the Health Professional, but rather in the sense of a pathway that does not lead to sanctions for non-compliance to protocols and guidelines.

The state is putting ethnic Pakistanis at-risk by its ascription of cultural difference onto British born individuals largely on the amount of melanin in their skin. I have spoken with many individuals who not only feel British, they are British; they were born here, they were educated here and they will, in the vast majority of cases, live out their whole lives in Britain. Yet they are confused by equal opportunities forms – which tell them they are, in some way, alien or 'other'. When they approach the NHS they are met by individuals who are told to adhere to protocol – or else. They are prevented from full access, by individuals often from their 'own' people, who help perpetuate the myth that '…they don't speak English…' One GC has often angered individuals, who see themselves as 'natives' – native Scots - by offering translators or 'someone from their community to sit in…' I argue this amounts to a perpetuation of institutional racism. The NHS, by its knee-jerk attempts to remove institutional racism, is perpetuating it with every new initiative. Initiatives were

identified as problematic by Alexander (1999), yet initiatives have been, and too often still are, at the heart of the interface between the two sides.

The combination of biomedicine, misunderstanding or misrepresentation of 'exotic' marriage customs and the perpetuation of the language myth has put, and is putting, members of a significant minority of the British population's reproductive health at-risk. All too frequently Health Professionals have to make decisions often based on unfounded assumptions about ethnic Pakistanis'[231] and particularly their ability to communicate and understand the complexities of their own genetic health. I would argue that this has wider implications for communication and understanding in contemporary British society, particularly with regard to the wider risks inherent in the ascriptive nature of audit culture.

[231] I suggest this also applies to many other minority ethnic groups in contemporary Britain.

Some recommendations:

I was asked many, many times by informants from both sides: '...OK, so what would *you* do?' or some close variant. For this reason, based on my findings, I offer the following suggestions:

- The majority of ethnic Pakistanis in Britain are British – treat them as such. By this I mean if, for example, their accent is strong asking them to speak more slowly – as would be the case with a Geordie[231] or a Scouse[232] or a Glaswegian.[233] Do not ask them if they would like an interpreter or someone from 'their community' to sit-in.

- Eradication of adaptive mutations from the genome is possible but undesirable. More time should be spent on education and developing an informed public debate, before such decisions are taken.

- Cease practices of ascription, based on phenotype. It is rude, offensive, divisive and promotes institutional racism

- Essentially: Do nothing, but do it better.

To repeat, I was told by a mother of four [when we first met she was pregnant with her third child] on my very first day in the field [and too many others to mention over the course of the research] that:

'...all we want is to be treated like everyone else...'

I would very much like this thesis to make a contribution to a process that granted her this simple wish.

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[231] Someone born in Newcastle-upon-Tyne.
[232] Someone born in Liverpool.
[233] Someone born in Glasgow.

Appendix

Appendix 1

Suppose that the country is preparing for the outbreak of an unusual disease, which is expected to kill 600 people. Two alter- native programmes are available to fight the disease. If the first programme (A) is adopted 200 people will be saved. If the second programme (B) is adopted there is a one-third probability that 600 people will be saved and a two-thirds probability that no people will be saved. Which of the two programmes do you prefer? Suppose further that there is a third programme (C) which, if adopted, will lead to 400 people dying, and a fourth programme (D), which gives a one-third probability that nobody will die and a two-thirds probability that 600 people will die. Which of programmes C and D do you prefer? In Tversky and Kahneman's study 75 per cent of physicians chose programme A over programme B, and 67 per cent chose programme D over programme C. But of course on close examination A and C are identical options as are B and D. Thus it can be seen that even health professionals can be much affected by the way in which probability information is presented.

Taken from Lay, P. (1988) **Communicating with Patients** (London: Chapman & Hall) pp160

Appendix 2

'Talking Scotland is a series of short programmes transmitted across Scottish TV and Grampian TV covering issues of importance to Scottish people.

The series is sponsored by the Scottish Executive and can be seen after the news bulletins at 3.05pm and 6.25pm on weekdays…'

Text downloaded: 9th May 2004, from Talking Scotland website

Uzma Alam 1: transcript of advertisement/video clip
http://talkingscotland.com/content/default.asp?page=s28_4

I was born and brought up in Glasgow but my parents are originally from Pakistan.

My ethnic origin is Pakistani but as far as identity goes, I would regard myself just as Scottish as anyone else from the indigenous community in Scotland.

I think my identity and what I'd called myself is a Scottish Muslim, that's what's important to me.

It's funny when you apply for a job and there are ethnic monitoring forms and you have to tick to say if you are white or if you're a Pakistani or Bangladeshi or an Indian or Afro-Caribbean, I sometimes sit and think "what am I?", it can be a bit confusing, we all have multiple identities.

I am not too sure which box to tick but, because of my ethnic origin, I always tick Pakistani but sometimes I have to think about it.

I could be a Scottish Asian but for me, most important, is that I'm Muslim, that's my faith and because I was born and brought up in Scotland, I regard myself as Scottish.

Uzma Alam 2: transcript of advertisement/video clip
http://talkingscotland.com/content/default.asp?page=s28_5

I decided to wear hijab in my first year at university that was almost six years ago and I've been wearing it ever since.

I decided to wear it as it was something I wanted to do, it was a personal choice.

I felt that as a Muslim it was part of my identity, it was part of my faith, it was an obligation to my religion to wear it.

I felt it gave me a lot of confidence as well.

Obviously there was more racism with the hijab than without it because you're a visible minority, you're visibly wearing something different.

If they don't understand why I wear the headscarf they should come up and ask, I wouldn't mind. I wouldn't mind at all. It's all about sharing knowledge at the end of the day and getting rid of people's negative stereotypes about Muslims or about myself.

Just the other day actually I was standing at the underground and a gentleman selling the Big Issue came up to me and asked me why I was wearing the headscarf.

I was actually quite happy that he did.

Appendix 3

WHY DOES THE CYCLE CONTINUE?

We have all grown up with stories of how our parents arrived in England 30 to 40 years ago to make a better life for themselves and their families, to educate their sons and daughters, so that their children could have a better life than them.

This story is the same for all emigrates whether Greek, Turkish, Asian or any other race.

Along the way a large percentage of these families have had to deal with the birth of a thalassaemic child. These parents now have to cope not only with surviving in a foreign country but also with the medical, emotional and spiritual problems associated with the birth of a thalassaemic child.

How do you explain to a parent that their child could probably die before his or her teens, and the only treatment is long and painful. How do you explain to a parent that God is not punishing them. How does a parent explain to their young child that they need to do their treatment to live, wishing all the time that you could take the pain of the needle away from that child.

When my parents arrived in England thalassaemia was unknown except to very few people. There was no screening or counselling programmes or any community education.

Why then , thirty years on, and with all the information and health programmes available, when I speak to my peers, all educated people from communities that thalassaemia affects, am I told that they've never heard of thalassaemia or that other great comment " We don't have that in our family". Why do I still see thalassaemic children being born.

We have all grown up with or know of some one who has thalassaemia and yet we won't go and have a simple blood test to see if we carry the gene. Then we marry and produce a new generation of thalassaemic children because our partners also don't know if they are carriers and so the cycle continues.

You can not tell whether some one carries the thalassaemia gene just by looking at there eyes, or by listening to your elders saying you haven't got it. Only a simple blood test will tell you whether you are a carrier or not.

Thalassaemia in the majority of case's is incurable but it is preventable.

Remember our parents had the excuse of no information and no education what's our excuse.

Michael Michael

UK Thalassaemia Society
http://www.ukts.org/pages/cycle.htm

Appendix 4

[redacted] NHS Trust
West of Scotland
Regional Genetics Service

[redacted]

NHS
[redacted]

[redacted]

Haemoglobinopathy Genetic Counselling Service
[redacted]

e-mail: [redacted]

MvM/JB/.....
Please quote the above number when contacting us.

To the parents of a child who has beta thal trait

Beta Thalasaemia Trait

Dear

You may remember that you came to see me in because XXX was found to have a Beta Thalassaemia trait.
As promised, I will summarise the conversation we had .

We discussed that the Beta Thalassaemia trait, like our colouring, general body build and other physical characteristics, are passed on in families from parent to child through genes. Genes are tiny bits of information contained in the father's sperm and the mother's egg and form the blue print for a new baby. Genes come in pairs. For each characteristic there are genes from each parent. The genes we are concerned with here determine HAEMOGLOBIN,- substances which carry oxygen in your blood and give it the red colour. This word is often shortened to Hb.

When a person has one usual gene and one Beta Thalassaemia gene they are called carriers or trait carriers. Having this gene **will not make them ill or affect their health**.

It has to be remembered that all people in the world carry some alterations in their 20.000 genes. So in fact we are all carriers of something. As yet we can not test for the majority of these gene changes but fortunately we can detect the altered gene that causes a Thalassaemia trait and are therefore able to give more information.

When both partners are carriers of an altered gene, there is a 1 in 4 chance of having a child who carries both copies of the unusual genes. In the case of Thalassaemia this could cause very severe anaemia. We found that Mr xxx does not carry an unusual haemoglobin trait, so it is unlikely that you will have affected children in future pregnancies. However there will be still a 1 in 2 chance, of the children inheriting the Beta Thalassaemia trait from Mrs xxx

As XXX is a carrier it would be prudent to remind him, in the far future, to invite his partner to be tested **before starting a pregnancy.** If the couple are both carriers they

could receive genetic counselling and further investigations to determine how this is going to affect them.

I believe your were given a Haemoglobinopathy card for ..... **Could you please present the card to your doctor and to hospital staff whenever you attend for treatment.** This would prevent repeated testing and inappropriate treatment. A health professional who does not know that you carry Beta Thalassaemia could think that you are short of iron because you have smaller red bloodcells. Carriers of a Thalassaemia trait need a special blood-test (serum ferritin test) to diagnose iron deficiency. You should take iron only when this test shows that you are short of iron.

We did not detect other conditions in your family which may warrant further genetic counselling or testing.

Please also keep this letter in a safe place so that you can refer to it later or show it to health professionals who may wonder what you have been told by us.

I have enclosed a booklet for xxx , which can be given to him when he is old enough to understand the implications of being a carrier. Please feel free to contact me if I can provide more information.

Best wishes for the future

Yours sincerely

[redacted]
Senior Genetic Counsellor for the Haemoglobinopathies.

CC: GP
Referral agent

Appendix 5

Appendix 6

APoGI
Haemoglobin Gene Variants

Guidance for Users

Information is provided both in a very simple format and in detail.

The materials can be used as aids to the counselling process, but also have other uses.

- For each carrier diagnosis there is one sheet. Each person with a carrier diagnosis should receive the appropriate sheet or equivalent written information. A copy should also be sent to the family doctor. These sheets are also suitable for issue by the diagnosing laboratory, to accompany results.
- For precise carrier diagnoses there is also a 15-page booklet with full information
- The reproductive implications of each carrier diagnosis (if a carrier's partner is not a carrier, carries the same haemoglobin disorder or carries a different haemoglobin disorder) are also explained on single sheets. Whenever a carrier's partner is tested, the appropriate sheet should be issued to the couple whether or not the results indicate a genetic risk. A copy should also be sent to the family doctor.
- For "risk combinations" - carrier combinations that generate a risk of a child with a significant haemoglobin disorder - there is a complete booklet explaining the risk, the condition concerned, its management, and (when appropriate) possibilities for prevention. The relevant booklet can be used as a aide in the counselling process, and given to each carrier couple to keep after counselling. Space is provided in these booklets to record the couple's precise haematological and DNA results, and the issuing centre. The aim is to promote prompt and accurate risk assessment, and continuity of care in the future.

Carriers should be advised to keep all information issued with their personal papers for future reference, especially in case of a pregnancy.

Please** contact APoGI **if you are uncertain about the appropriateness of a particular document to a particular case.

Safeguards for Health Professionals

The information materials are correct only if the diagnosis is correct. There is usually little doubt about a diagnosis provided by an experienced laboratory, but mistakes can happen. We recommend the following rules in counselling for haemoglobin disorders:

1. Always see a copy of the original results, or a haemoglobinopathy card giving the address of the centre where the diagnosis was made, or a letter in which the results were written by a competent person, before providing counselling. Errors are easily made if counselling is based on hearsay, however authoritative the source of verbal information may be.
2. If you are not sure that the laboratory where the test was done is definitely reliable, arrange for a repeat test before providing counselling. If the diagnosis has been made in a laboratory other than the one you habitually work with, especially one in an area where there are not many people in ethnic groups at risk, consider carefully if the results are really reliable. Errors can occur when there is not a large haemoglobinopathy workload or if recognised recommendations for screening are not followed. They can happen even in a laboratory that belongs to a quality control programme or is sited in a university hospital. ***Repeat the test if there is any doubt at all.***

Appendix 6

Appendix 7

Exegesis of Islamic terms used.

Alim

A learned person in Islam, scholar.
(http://www.usc.edu/dept/MSA/reference/glossary/term.ALIM.html)

Assalamu alaikum

This is an expression Muslims say whenever they meet one another. It is a statement of greeting with peace. The meaning of it is: "Peace be upon you."

Muslims try to establish peace on earth even through the friendly relation of greeting and meeting one another.

The other forms are: "Assalamu 'Alalikum Wa Rahmatullah," which means: "May the peace and the Mercy of Allah be upon you," and "Assalamu Alalikum Wa Rahmatullahi Wa Barakatuh," which means:"May the peace, the mercy, and the blessings of Allah be upon you." (http://www.usc.edu/dept/MSA/reference/glossary/term.ASAK.html)

Eid

The word 'Eid is an Arabic name to mean a festivity, a celebration, a recurring happiness, and a feast. In Islam, there are two major 'Eids namely the feast of Ramadhan (*'Eid Al-Fitr*) and the Feast of Sacrifice (*'Eid Al-Adhha*). The first 'Eid is celebrated by Muslims after fasting the month of Ramadhan as a matter of thanks and gratitude to Almighty Allah. It takes place on the first day of Shawwal, the tenth month of the lunar calendar. The second 'Eid is the Feast of Sacrifice and it is to be celebrated for the memory of prophet Ibrahim trying to sacrifice his son Isma'il (Ishmael). This 'Eid lasts four days between the tenth and the thirteenth day of *Zul-Hijjah*, the twelfth month of the lunar calendar.
(http://www.usc.edu/dept/MSA/reference/glossary/term.EID.html)

Fatwa
Legal opinion concerning Islamic Law.
(http://www.usc.edu/dept/MSA/reference/glossary/term.FATWA.html)

Hadith

Reports on the sayings and the traditions of Prophet Muhammad (s.a.w.) or what he witnessed and approved are called Hadith. These are the real explanation, interpretation, and the living example of the Prophet (s.a.w.) for teachings of the Qur'an. His sayings are found in books called the Hadith books. Some famous collectors of Hadith are Imam Al-Bukhari, Imam Muslim, Imam An-Nasa'i, Imam Abu Dawood, Imam At-Tirmizi, and Imam Majah. There are many others.
(http://www.usc.edu/dept/MSA/reference/glossary/term.HADITH.html)

Hadith qudsi

The Hadith Qudsi are hadith's in which the Prophet says that Allah says so and so. The meaning of the these hadith was revealed to the Prophet but he put them in his own words, unlike the Qur'an which is the word of Almighty Allah and the Prophet conveyed it

exactly as it was revealed to him.
(http://www.usc.edu/dept/MSA/reference/glossary/term.HADITHQ.html)

Hafiz (Hifz)

The Arabic root of this word is Hafiza which means to memorize. In the religious sense, Muslims try to memorize the whole Qur'an. Any person who achieves this task is called Hafiz.

A Hafiz is recognized by his community and is given certain privileges. There millions of Muslims who make Hifz of the whole Qur'an.
(http://www.usc.edu/dept/MSA/reference/glossary/term.HIFZ.html)

Hajj

Hajj is an Arabic word which means the performance of pilgrimage to Makkah in Arabia. It is one of the five pillars of Islam. A Muslim is to perform Hajj at least once in his/her life, if means and health allow.

There are rules and regulations and specific dress to be followed. It is to take place during the last month of the lunar calendar called the month of Zul-Hijjah.
(http://www.usc.edu/dept/MSA/reference/glossary/term.HAJJ.html)

Halal

Something that is lawful and permitted in Islam.
(http://www.usc.edu/dept/MSA/reference/glossary/term.HALAL.html)

Haraam

Something which is unlawful or prohibited in Islam.
(http://www.usc.edu/dept/MSA/reference/glossary/term.HARAAM.html)

Imam

A religious leader, any person who leads a congregational prayer is called an Imam. A religious leader who also leads his community in the political affairs may be called an Imam, an Amir, or a Caliph. However, an Imam is not infallible. He is responsible for his mistakes to all the members of the community and above all he is responsible to Almighty Allah. (http://www.usc.edu/dept/MSA/reference/glossary/term.IMAM.html)

Injil

The revelations that were sent down during the time of Prophet Isa (Jesus). It is referred to as the New Testament.
(http://www.usc.edu/dept/MSA/reference/glossary/term.INJIL.html)

In sha' allah

When a person wishes to plan for the future, when he promises, when he makes resolutions, and when he makes a pledge, he makes them with permission and the will of Allah. For this reason, a Muslim uses the Qur'anic instructions by saying "In Sha ' Allah." The meaning of this statement is: "If Allah wills." Muslims are to strive hard and to put

their trusts with Allah. They leave the results in the hands of Allah. *Other Commonly Used Spellings: INSHA ALLAH ,INSHAA ALLA, INSHA ALLA, IN SHA' ALLA* (http://www.usc.edu/dept/MSA/reference/glossary/term.INSHA.html)

Islam

Islam is an Arabic word the root of which is Silm and Salam. It means among others: peace, greeting, salutation, obedience, loyalty, allegiance, and submission to the will of the Creator of the Universe.

Islam is the last and final religion to all mankind and to all generations irrespective of colour, race, nationality, ethnic background, language, or social position.

The religion of Islam is not to be confused with Mohammedanism. The latter is misnomer to Islam. Muslims do not accept this name as it gives wrong information about Islam and Muslims. (http://www.usc.edu/dept/MSA/reference/glossary/term.ISLAM.html)

Jahil (Jahiliyyah)

Means ignorant. Jahiliyyah refers to the pre-Islamic era that existed in Arabia. It is a combination of views, ideas, and practices that totally defy and reject the guidance sent down by God through His Prophets.
(http://www.usc.edu/dept/MSA/reference/glossary/term.JAHIL.html)

Jihad

It is an Arabic word the root of which is Jahada, which means to strive for a better way of life. The nouns are Juhd, Mujahid, Jihad, and Ijtihad. The other meanings are: endeavour, strain, exertion, effort, diligence, fighting to defend one's life, land, and religion.

Jihad should not be confused with Holy War; the latter does not exist in Islam nor will Islam allow its followers to be involved in a Holy War. The latter refers to the Holy War of the Crusaders.

Jihad is not a war to force the faith on others, as many people think of it. It should never be interpreted as a way of compulsion of the belief on others, since there is an explicit verse in the Qur'an that says: "There is no compulsion in religion" Al-Qur'an: Al-Baqarah (2:256).

Jihad is not a defensive war only, but a war against any unjust regime. If such a regime exists, a war is to be waged against the leaders, but not against the people of that country. People should be freed from the unjust regimes and influences so that they can freely choose to believe in Allah.

Not only in peace but also in war Islam prohibits terrorism, kidnapping, and hijacking, when carried against civilians. Whoever commits such violations is considered a murderer in Islam, and is to be punished by the Islamic state. During wars, Islam prohibits Muslim soldiers from harming civilians, women, children, elderly, and the religious men like priests and rabies. It also prohibits cutting down trees and destroying civilian constructions. (http://www.usc.edu/dept/MSA/reference/glossary/term.JIHAD.html)

Mahram

A mahram refers to the group of people who are unlawful for a woman to marry due to marital or blood relationships. These people include:

1. Her permanent Mahrams due to blood relationship, and those seven are: her father, her son (who passed puberty), her brother, her uncle from her father's side, her brother's son, her sister's son, and her uncle from her mother's side.
2. Her Radha' Mahrams due to sharing the nursing milk when she was an infant, and their status is similar to the permanent seven Mahrams (i.e. nothing can change their status).
3. Her (in law) Mahrams because of marriage and they are: her husband's father (father in law), her husband's son (step son), her mother's husband (step father), and her daughter's husband.

These categories of people, along with the woman's husband, form the group of allowable escorts for a Muslim woman when she travels.
(http://www.usc.edu/dept/MSA/reference/glossary/term.MAHRAM.html)

P.B.U.H.

These letters are abbreviations for the words Peace Be Upon Him which are the meaning of the Arabic expression " 'Alaihis Salam", which is an expression that is said when the name of a prophet is mentioned.

This expression is widely used by English speaking Muslims. It is to be noticed here that this expression does not give the full meaning of "Salla Allahu 'Alaihi Wa Sallam". Therefore it is recommended that people do not use (p.b.u.h.) after the name of Prophet Muhammad (s.a.w.); they should use "Salla Allahu 'Alaihi Wa Sallam" instead, or they may use the abbreviated form of (s.a.w) in writing.
(http://www.usc.edu/dept/MSA/reference/glossary/term.PBUH.html)

Qur'an

The holy book of Qur'an is called the Qur'an. It was revealed unto Muhammad (s.a.w) from Allah through angel Gabriel (Jibril) for a period of 23 years. There is only one Qur'an in the whole world and it is in Arabic language. The Qur'an has one text, one language, and one dialect. It has been memorized by millions of Muslims in different parts of the world.

The Qur'an is composed of 114 Surah (chapters). It is to be read and recited with rules and regulations. When to be touched and to be recited, a Muslim to be in a state of cleanliness and purity.

The authenticity and the totality of the Qur'an have been documented and recognized. The Qur'an can not be translated at all as the Qur'an is the exact words of Allah. Any translation is considered to be the explanation to the meaning of the Qur'an.

The Qur'an is so rich and comprehensive in matter that it can easily guide men and women in all works of their life. It is the ultimate source of guidance for people in all aspects of their spiritual and material lives.

The names and attributes that are given to the Qur'an in the Qur'an speak for themselves. The Qur'an is also described to be bounteous, glorious, mighty, honoured, exalted,

purified, wonderful, blessed, and confirming the truth of previous revelations. The Qur'an has practically proved the truth and effectiveness of all of its names and epithets in the life of all true believers, who practiced its teachings sincerely and devoutly.

The Qur'an has a Universal appeal, regardless of people's colour, creed, nationality, and geographical divisions of the world. The goal of life, as addressed in the Qur'an, is to live according to what Allah has created us for, which is to worship Allah, and to obey his commandments in this life, which are of course, in the interest of people, and to gain going to Heaven and escape going to Hell in the hereafter. The real success is going to Heaven and the real failure is going to Hell, as the Qur'an states.

Those who are entirely lost in their material gains and luxury, without cultivating their spiritual and moral qualities, are declared by Allah (s.w.t.) to be like animals, rather worse than them. The ones who do not believe in Allah or follow His commandments are also described in many places of the Qur'an to be dead, deaf, mute, and blind. The real living, hearing, speaking and seeing are caused by the true belief in the heart. So our need for learning, studying, and following the Qur'an should come before our need for breathing, drinking and eating to survive, because life without such guidance is a miserable life that leads to eternal punishment.
(http://www.usc.edu/dept/MSA/reference/glossary/term.QURAN.html)

S.A.W.S /S.A.A.S.

These letters are abbreviations for the words "Salla Allahu 'Alaihi Wa Sallam", which means: may the blessing and the peace of Allah be upon him.

When the name of Prophet Muhammad is mentioned, a Muslim is to respect him and invoke this statement of peace upon him.
(http://www.usc.edu/dept/MSA/reference/glossary/term.SAW.html)

Shaikh

The word Shaikh is a title or a nickname for an elderly person or a religious leader in a community. This title is also given to a wise person.

The meaning of the word Shaikh has been distorted, misused, and abused by some mass media to reflect the wrong meanings.
(http://www.usc.edu/dept/MSA/reference/glossary/term.SHAIKH.html)

Sunnah

In general, the word Sunnah means habit, practice, customary procedure, or action, norm and usage sanctioned by tradition. In specific, any time the word Sunnah is mentioned, it is to refer to Prophet Muhammad (s.a.w.). Here it means his sayings, practices, living habits. The Hadith are reports on the Sunnah.

The two major legal sources of jurisprudence in Islam are the Qur'an and the Sunnah.

The Sunnah may confirm what is mentioned in Qur'an, interpret and explain it, specify what is meant by some general verses, limit and restrict the meaning of some verse in it, or may explain something that has been revealed in Qur'an.

The Sunnah has a high authority in Islam; and Allah in many places in the Qur'an orders the Muslims to follow the teachings of Prophet Mohammad (s.a.w.). (http://www.usc.edu/dept/MSA/reference/glossary/term.SUNNAH.html)

Surah

The Qur'an is composed of 114 chapters, each of which is called a Surah. The plural of Surah is called Suwar, which means chapters. (http://www.usc.edu/dept/MSA/reference/glossary/term.SURAH.html)

Ulama

The learned, knowledgeable people in Islam. Plural form of alim. (http://www.usc.edu/dept/MSA/reference/glossary/term.ULAMA.html)

Ummah

An ummah is a community or a people. It is used in reference to the community of Believers or Muslims. (http://www.usc.edu/dept/MSA/reference/glossary/term.UMMAH.html)

Wa 'alaikumus salam

This is an expression that a Muslim is to say as an answer for the greeting. When a person greets another with a salutation of peace, the answer for the greeting is an answer of peace. The meaning of this statement is: "And upon you is the peace." The other expressions are: "Wa Alaikumus Salam Wa Rahmatullah." and "Wa 'Alaikums Salam Wa Rahmatullahi Wa Barakatuh." (http://www.usc.edu/dept/MSA/reference/glossary/term.WAKAS.html)

REFERENCES

AAA (1998) *Code of Ethics of the American Anthropological Association* (New York: AAA) http://www.aaanet.org/committees/ethics/ethcode.htm

Abdullah Yusuf Ali (1996) *The Meaning of The Holy Qur'an* (Maryland: Amana Publications)

Abdulrazzaq, Y. M. Bener, A. al Gazali, L. I. al Khayat, A. I. Micallef, R. Garber, T. 'A study of possible deleterious effects of consanguinity.' *Clinical Genetics*, 51(3), March 1997: 167-73

Acheson, R M (1984) *Health, Society and Medicine* (Oxford: Blackwell Scientific Publications)

Acheson, D (1998) *Independent Enquiry into Inequalities in Health Report* (London: The Stationary Office) http://www.official-documents.co.uk/document/doh/ih/ih.htm

Advisory Committee on Genetic Testing (1999) *Third Annual Report and Compendium of Guidance* (London: Department of Health) http://doh.gov.uk

Agutter, J. (16/12/2003) 'Good health' *Daily Mail*, pp 36-7

Ahmad, W I U (1991) 'General Practitioners' Perceptions of Asian and Non-Asian Patients' *Family Practice* vol. 8, no. 1, pp 52-56

Ahmad, W I U (Ed) (1993) *Race and Health in Contemporary Britain* (Buckingham: Open University Press)

Ahmad, W I U (1994) 'Reflections on the Consanguinity and Birth Outcome Debate' *Journal of Public Health Medicine*, Vol. 16, No 4, pp. 423-28

Ahmad, W I U (1996) 'Consanguinity and Related Demons: Science and Racism in the Debate on Consanguinity and Birth Outcome' in Samson, C & South, N (Ed) (1996) *The Social Construction of Social Policy Methodologies, Racism, Citizenship and the Environment* (Houndmills: Macmillan Press)

Aiello, L & Dean, C (1990) *An Introduction to Human Evolutionary Anatomy* (London: Academic Press)

Alderson, P (1998) 'The importance of theories in health care' *British Medical Journal*, vol. 317, 10/10/98 1007-1010

Alexander, Z (1999) *The Department of Health: Study of Black, Asian and Ethnic Minority Issues* http://www.doh.gov.uk/race-equaliy/ziggystudy.pdf

Anderson, R (1996) *Magic, Science and Health* (Fort Worth: Harcourt Brace)

Angastiniotis, M et al (1995) 'Prevention and Control of Haemoglobinopathies' *Bulletin of the World Health Organisation* 73(30), pp. 375-86

Anwar, M (1979) *The Myth of Return: Pakistanis in Britain* (London: Heinemann)

Anwar, M (1990) 'The Participation of Asians in the British Political System' in Clarke, C Peach, C Vertovec, S (Ed.) (1990) *South Asians Overseas, Migration and Ethnicity* (Cambridge: Cambridge University Press)

AOL News (22/10/2003) *Inquiry urged over police documentary* http://aol.com/news

ARC (Antenatal Results and Choices) (2004) www.arc-uk.org

ASA (1999) *Ethical Guidelines for Good Research Practice* (London: Association of Social Anthropologists of the UK and the Commonwealth) http://www.theasa.org/ethics.htm

Asad, T. (1979) 'Anthropology and the analysis of Ideology', *Man* 14, 607-27

Asad, T. (1986) *The Idea of an Anthropology of Islam* (Washington DC: CCAS Georgetown University)

Ashcroft, R E (2000) Genetic Information and "Genetic Identity" in Thompson & Chadwick (1999) *Genetic Information* (New York: Kulwer Academic/Plenum Publishing)

Atkin, K Ahmad, W I U Anionwu, E N (1998) 'Screening and Counselling for Sickle Cell Disorders and Thalassaemia: The Experience of Parents and Health Professionals', *Social Science Medicine, Vol. 47, No. 11, pp. 1639-51*

Atkin, K & Ahmad, W. (2000) Pumping iron: compliance with chelation therapy among young people who have thalassaemia major *Sociology of Health & Illness*, vol. 22, No. 4, pp. 500-524

Atkinson, P. (1994) 'Rhetoric as skill in a medical setting' in Bloor, M & Taraborrellia, P. (Ed.)(1994) *Qualitative Studies in Health and Medicine* (Aldershot: Avebury)

Balarajan, R Soni Raleigh, V (1989) '*Perinatal Mortality in England and Wales: variations by Mother's Country of Birth (1982-1985)*' *Health Trends* 21, 79-84

Ballard, T & Ballard, C. (1977) 'The Sikhs – the development of South Asian settlement in Britain' in Watson, J.L. (Ed) (1977) *Between Two Cultures* (Oxford: Blackwell)

Ballard, R (1990) 'Migration and Kinship: the differential effect of marriage rules on the process of Punjabi migration to Britain' in Clarke, C Peach, C Vertovec, S (Ed.) (1990) *South Asians Overseas, Migration and Ethnicity* (Cambridge: Cambridge University Press)

Ballard, R et al (1994) *Desh Pardesh, The South Asian presence in Britain* (London: Hurst & Co)

Barnes C et al (1999) *Exploring Disability* (Cambridge: Polity Press) pp. 21-56

Baudrillard, J (1983) *Simulations* (New York: Semiotext[e])

Baumann, G (1999) *The Multicultural Riddle: rethinking national, ethnic and religious identities* (London: Routledge)

Bayne-Smith, M (1996) *Race, Gender and Health* (Thousand Oaks: Sage Publications)

BBC News (25/04/2001) *Tories renew asylum attacks* http://news.bbc.co.uk/1/hi/uk_politics/talking_politics/1296383.stm

BBC News (20/09/2001) *Salmond in backlash warning* http://news.bbc.co.uk/1/hi/in_depth/uk_politics/2001/conferences_2001/snp/1554173

BBC News (21/09/2001) *Swinney's call for racial tolerance* http://news.bbc.co.uk/1/hi/in_depth/uk_politics/2001/conferences_2001/snp/1556340

BBC News (22/09/2001) *Attacks 'no excuse for racist violence'* http://news.bbc.co.uk/1/hi/uk/1583319.stm

BBC News (22/2/2002) *Hashmi decision sparks ethics row*

http://news.bbc.co.uk/1/hi/health/1836827.stm

BBC News (12/09/2002) *Italian police arrest terror suspects*

http://news.bbc.co.uk/1/hi/world/europe/2253097.stm

BBC News (16/10/2002) *Sidney's Muslims fear revenge attacks*

http://news.bbc.co.uk/1/hi/world/asia-pacific/23331947.stm

BBC News (16/7/2003) *Aborted foetus could provide eggs*

http://news.bbc.co.uk/1/hi/health/3031800.stm

BBC News (22/7/03) *Targets blamed for blindness*

http://news.bbc.co.uk/1/hi/politics/3085105.stm

BBC News (11/06/2004) '*Bradford gives BNP a rare boost*'

http://news.bbc.co.uk/1/hi/uk_politics/3799697.stm

BBC News (16/07/2004) '*BNP leader repeats Islam attack*'

http://news.bbc.co.uk/1/hi/uk/3898695.stm

BBC News (29/07/2004) *'BNP councillor loses driving job'*

http://news.bbc.co.uk/1/hi/england/west_yorkshire/3937661.stm

Beck, U (1992) *Risk Society: towards a new modernity* (London: Sage)

Bell, J (1998) 'The New Genetics in Clinical Practice' *British Medical Journal*, 21 February, pp. 618-20

Bhardwaj, M. R. (1995) *Colloquial Panjabi, a complete language course* (London: Routledge)

Bhopal, R (1998a) 'Spectre of Racism in Health and Health Care: Lessons from History and the United States', *British Medical Journal*, Vol. 316, 27 June, pp. 1979-3

Bhopal, R. et al (1998b) 'Religious Circumcision on the NHS: opinions of Pakistani People in Middlesbrough, England' *Journal of Epidemiology and Community Health, 52, 758-759*

Bittles, A H (1983) 'The intensity of human inbreeding depression', *The Behavioural and Brain Sciences,* vol. 1, pp 103-4

Bittles, A. H. et al 'Consanguinity as a determinant of reproductive behaviour and mortality in Pakistan', *International Journal of Epidemiology* (1993) June; 22(3): 463-7

Bittles, A.H. (1998) 'Human inbreeding: a predictable story full of Surprises', *Symposium on Health & Ethnicity*, Oxford Brookes, 16-17 April

Bourdieu, P. (1991) *Language and Symbolic Power* (Cambridge: Polity Press)

Bourke, J. (1994) *Working Class Culture in Britain 1890-1960* (London: Routledge)

Bowes, A M (1996) 'Evaluating and Empowering Research Strategy: Reflections on Action-Research with South Asian Women', *Sociology Research Online* vol. 1, no. 1 http://socresonline.org.uk/socresonline/1/1/1.html

Bowes, A. Naira Dar Duncan Sim (1998) *'Too white, too rough, and too many problems...': A Study of Pakistani Housing in Britain* (Stirling: University of Stirling)

Bowler, I (1994) 'Midwifery - independent practice in the 1990s?' in Bloor, M & Taraborrellia, P. (Ed.)(1994) *Qualitative Studies in Health and Medicine* (Aldershot: Avebury)

Bradby, H (1996) 'Genetics and Racism' in Marteau, T. & Richards, M. (1996) *The Troubled Helix: social and psychological implications of the new human genetics* (Cambridge: Cambridge University Press)

Bradby, H & Williams, R (1999) 'Behaviours and Expectations in Relation to Sexual Intercourse Among 18-20 Year Old Asians and Non-Asians' *Sex Transmission Information, 75, 162-7*

Bradby, H 'British Medical Journal (1999) 'The Genomic Challenge. It's huge and the NHS is poorly prepared to meet it', *British Medical Journal,* Vol. 318, 6 February

Bryan, J. (1997) *South Bank Ethnic Minority Housing Needs Assessment –1996* (Middlesbrough: Northern Consortium of Housing Authorities)

Cain, P. J. & Hopkins, A. G. (2002) *British imperialism, 1688-2000* (Harlow: Longman)

Caplan, P. (Ed) (2000) *Risk Revisited* (London: Pluto Press)

Carsten, J. (2000) *Cultures of Relatedness* (Cambridge: Cambridge University Press)

Carter, B & Green, M (1996) 'Naming Difference: Race-thinking, Common Sense and Sociology' pp 57-67 in Samson, C. & South, N. (1996) *The Social Construction of Social Policy Methodologies, Racism, Citizenship and the Environment* (Houndmills: Macmillan)

Carrier, J (ed) (1995) *Occidentalism: Images of the West* Oxford: Oxford University Press)

Chadwick, R & Tadd, W. (1992) *Ethics and Nursing Practice* (London: Macmillan)

Charmaz, K. 'Discovering' Chronic Illness: Using Grounded Theory', *Social Science Medicine* (1990) Vol. 30, No. 11, pp 1161-1172

Cauquelin, J. et al (Ed) (2000) *Asian Values an Encounter with Diversity* (Richmond: Curzon)

Chitty, LS Winter R M (1989) 'Perinatal Mortality in Different Ethnic Groups', *Archives of Disease in Childhood* 64: 1036-41

Clarke, C. et al (Ed) (1990) *South Asians Overseas, Migration and Ethnicity* (Cambridge: Cambridge University Press)

Cleveland County Research & Intelligence (1979) *Inner City Health Education Survey* (Middlesbrough: Cleveland County Council)

Cleveland County Research & Intelligence (1982a) *Asian Survey: Education, Housing, Health and Other Community Provision* (Middlesbrough: Cleveland County Council)

Cleveland County Research & Intelligence (1982b) *Asian Survey: Country of Birth, Demographic and Household Structures* (Middlesbrough: Cleveland County Council)

Cleveland County Research & Intelligence (1982c) *Asian Survey: Economic Activity* (Middlesbrough: Cleveland County Council)

Cleveland County Research & Intelligence (1982d) *Asian Survey: Community Relations* (Middlesbrough: Cleveland County Council)

Cleveland County Research & Intelligence (1982e) *Asian Survey: Summary Report* (Middlesbrough: Cleveland County Council)

Cohen, A. P. (1985) *The Symbolic Construction of Community* (London: Routledge)

Commission for Racial Equality (2002) *Equal Futures: children and young people building racial equality* (Edinburgh: Children in Scotland)

Connor, J. M. & Ferguson-Smith, M.A.(1993) *Essential Medical Genetics, 4th Ed* (London: Blackwell Science)

Cookson, C (10/5/1998) 'One more step but not Journey's end', *Financial Times*

Cooper, Y (24/01/2001) *Minister Welcomes Report on Ethnic Health Inequalities* http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/

Cooter, R (2003) *Tracking Medical Ethics* in *'From Victoria to Viagra: 150 of medical progress'* (London: Wellcome Trust)

Cramer, D et al (1997) 'Social Support and Marital Well-being in an Asian Community' *Social Policy Research, 128, September*

Crawford, R. (1977). 'You are dangerous to your health: the ideology and politics of victim blaming', *International Journal of Health Services*, 7, 663-80.

Cruckshank, J. D. 'Ethnic differences in cardiovascular disease and diabetes: nature rather than "sick" genes?' *Symposium on Health & Ethnicity*, Oxford Brookes, 16-17 April 1998.

Culley, L & Dyson, S. (1993) '"Race", inequality and health', *Sociology Review*, vol. 3, no. 1

Currer, C. (1986) 'Concepts of Mental Well-being and Ill-being: The Case of Pathan Mothers in Britain' in Currer, C & Stacey, M. (Ed) (1986) *Concepts of Health, Illness, and Disease: A Comparative Perspective* (Oxford: Berg)

d'Agincourt-Canning, L (201) 'Experiences of Genetic Risk: disclosure and gendering of responsibility', *Bioethics* Vol. 15, No. 3, 231-247

Daily Mirror (07/10/2003) *English Live in Fear of Race-Hate Abuse,* pp 13

Daily Record (23/11/2002) *Racist Scum Caged* pp 17

Darr, A (1997) Consanguineous Marriage and Genetics: a positive relationship in Clarke, A & Parsons, E (Eds.) *Culture Kinship and Genes: towards cross-cultural genetics* (New York: St Martins Press) pp. 83-96

Darr, A Modell B (1988) 'The frequency of Consanguineous Marriage among British Pakistanis', *Journal of Medical Genetics* 25, pp. 186-190

Davies, S C 'The Haemoglobinopathies: impact upon black and Ethnic Minority People' in Hopkins, A & Bahl, V (Eds.) (1993) *Access to Healthcare for people from Black and Ethnic Minorities* (London: Royal College of Physicians) pp. 147-68

Department of Health (1998) *Inspection of Services to Ethnic Minority Children and Families* http://doh.gov.uk

Department of Health (1999a) *Executive Summary: Primary Health Care Services for children from Ethnic Minority Groups* http://doh.gov.uk

Department of Health (1999b) *Our Healthier Nation: Reducing Health inequalities: and Action Report* (London: Department of Health), 3.9

Department of Health (2000a) *Prenatal Genetic Testing* (Department of Health) http://doh.gov.uk

Department of Health (2000b) *Health Survey for England* http://www.doh.gov.uk

Department of Health (2000c) *The Race Equality Agenda of the Department of Health* http://www.doh.gov.uk/pub/docs/doh/ziggydhresp.pdf

Department of Health (2002) *Preimplantation Genetic Diagnosis (PGD)*

DeVita, P. R. (1992) *The Naked Anthropologist, tails from around the world* (Belmont: Wadsworth Publishing Co.)

Doherty, J et al (1992) *Postmodernism and the Social Sciences* (London: Macmillan)

Donahue, J.M. (1990) 'The Role of Anthropologists in Primary Health Care: Reconciling Professional and Community Interests' pp 79-93 in Coreil, J & Mull, J.D. (1990) *Anthropology and Primary Health Care* (Boulder: Westview Press)

Donnan, H (1988) *Marriage Among Muslims preference and choice in Northern Pakistan* (Leiden: E.J. Brill)

Donnan, H (1994) Marriage Preferences Among the Dhund of Northern Pakistan in Uberoi, P (1994) *Family, Kinship and Marriage in India* (Delhi: Oxford University Press) pp. 307-29

Douglas, M & Wildavsky, A (1982) *Risk and Culture* (Berkeley: University of California Press)

Douglas, M (1986) *Risk, Acceptability According to the Social Sciences* (London: Routledge & Kegan Paul)

Edwards, R H T (1999) 'Is it Time for an Illich Collaboration to Make Available Information on the Harms of Medical Care?', *British Medical Journal*, Vol. 318, 2 January, pp. 58

Eickelman, D. F. & Piscatori, J. (1996) *Muslim Politics* (Princeton N.J.: Princeton University Press)

Environment, Transport and the Regions, Dept of (2000) *New Deal for Communities Guidance for Racial Equality* (London: DETR)

Fardon, R (1992) Postmodern Anthropology? Or, an Anthropology of Postmodernity? In Doherty, J et al (1992) *Postmodernism in the Social Sciences* (London: Macmillan)

Fears, R Post, G (1998) 'Reasons to be Cheerful – and Careful', *Science and Public Affairs* Winter: 5-7

Featherstone, M et al (Ed) (1991) *The Body: social processes and Cultural Theory* (London: Sage Publications)

Foucault, M. (1976) *The Birth of Clinic: An Archaeology of Medical Perception* (London: Tavistock)

Fox, R. (1983) *Kinship & Marriage an anthropological perspective* (Cambridge: Cambridge University Press)

Gardner, K & Shaker, A (1994) 'I'm Bengali, I'm Asian, and I'm Living Here: the changing identity of British Bengalis' in Ballard, R et al (1994) *Desh Pardesh, The South Asian Presence in Britain* (London: Hurst & Co) pp. 142-164

Gardner, K (1995) *Global Migrants Local Lives: travel and transformation in Rural Bangladesh* (Oxford: Clarendon Press)

Genetics Interest Group (GIG) http://www.gig.org.uk

GeneWatch UK (2003) *Regulating Human Genetic Tests: Ten key questions* *http://www.genewatch.org/humangen/tests/10_questions.doc*

Gibson, W S (1977) *Bruegel* (London: Thames And Hudson)

Giddens, A. (1991) *Modernity and self-identity: self and society in the late modern age* (Cambridge: Polity)

Gill, P S & Modell, B (1998) 'Thalassaemia in Britain: a tale of two communities', *British Medical Journal* Vol. 317, pp. 761-2

Gillon, R. (1996) *Philosophical Medical Ethics* (Chichester: John Wiley & Sons)

Gold, E. R. (1996) *Body parts: property rights and the ownership of human biological materials* (Washington DC: Georgetown University Press)

Goldthorpe, J H (1987) *Social Mobility and Class Structure in Modern Britain* (Oxford: Clarendon Press)

Goodwin, R. (1997) *Social Support and Marital Well-being in an Asian Community* (London: YPS)

Gordon, D (Ed) (1999) *Inequalities in health: the evidence; the evidence presented to the Independent Inquiry into Inequalities in Health, chaired by Sir Donald Acheson* (Bristol: Policy Press)

Graham, H. (1984) *Women, Health and the Family* (Brighton: Wheatsheaf)

Graham, H. (Ed.) (2000) *Understanding Health Inequalities* (Buckingham: Open University Press)

Grant, J.C. Bittles A.H. 'The comparative role of consanguinity in infant and childhood mortality in Pakistan', *Annals of Human Genetics*, 61 (Pt 2) March 1997: 143-9

Green, E. et al (2003) *The Nisaa Project: Final Report* (Middlesbrough: University of Teesside)

Guardian, The (14/07/2001) Race tensions reach boiling point *The Editor* pp 5

Hall, S. (1993) 'Culture, Community and Nation.' *Cultural Studies,* no 7, pp 349-63

Hallowell, N (1999) 'Doing the right thing: genetic risk and responsibility', *Sociology of Health & Illness,* Vol. 21 (5), September 1999, pp. 597-621

Haralambos, M & Holborn, M (1995) *Sociology: Themes and Perspectives, 4th Ed* (London: Collins Educational)

Hardisty R. M. & Weatherall, D. J. (Ed)(1982) *Blood And Its Disorders 2nd Ed* (Oxford: Blackwell Scientific Publications)

Hardy, A (2001) *Health and Medicine In Britain Since 1860* (Houndmills: Palgrave)

Harper, P.S. (1999) *Practical Genetic Counselling* (Oxford: Butterworth Heinemann)

Harris, R et al (1998) *National Confidential Enquiry into Counselling for Genetic Disorders Homozygous Beta Thalassaemias, Great Britain, 1990 to 1994.* Report to the Department of Health from the Steering Committee

Hashmi, M. A. 'Frequency of consanguinity and its effect on congenital malformation - hospital based study', *Journal of the Pakistan Medical Association*, 47(3), March 1997: 75-78.

Hassall, O W, Tillyer, M L Old, J M (1998) 'Prevalence and molecular basis of α thalassaemia in British South Asians', *Journal of Medical Screening* Vol. 5, no. 1, pp. 31-3

Heinlein, R 1982) *Friday* (London: NEL)

Helman, C. G. (1990a) *Culture, Health and Illness: an introduction for health professionals* (London: Wright)

Helman, C (1990b) 'Cultural factors in health and illness' in McAvoy, B. R. & Donaldson, L. J. (1990) *Health Care for Asians* (Oxford: Oxford University Press)

Hickman, M et al (1999) 'Mapping the Prevalence of Sickle Cell and beta-thalassaemia in England: Estimating and Validating Ethnic-specific Rates', *British Journal of Haematology* 104 pp. 860-67

Hillery, G. (1955) 'Definitions of Community: Areasof Agreement'. *Rural Sociology* 20' 116-31

Hills, E. Hampshire, K. (2001) *South Bank Health and Social Services Community Needs Research Project 2000-1* (Redcar: Redcar & Cleveland Joint Finance)

Hodgson, J. 'All in Good Time, genomics and the future of healthcare', *Wellcome News 20 Q3 1999, 10-11*

Hodgson, J. 'People Power, population profiles and common diseases', *Wellcome News 20 Q3 1999, 18-19*

Holy, L (1996) *Anthropological Perspectives on Kinship* (London: Pluto Press)

Honeyman, M. 'Consanguinity and foetal growth in Pakistani Moslems' *Archives of Disease in Childhood* (1987) March: 62(3): 231-5

Household, N. (2002) *Genetics and You* (London: BBC Adult Learning)

Houtsma, M. T. et al (1927) *The Encyclopaedia of Islam* (Leyden: Late E. J. Brill Ltd)

Human Fertilisation and Embryology Authority and Advisory Committee on Genetic Testing *Consultation Document on Preimplantation Genetic Diagnosis* http://www.doh.gov.uk

Human Fertilisation and Embryology Authority (HFEA) (11/04/2003) *Court of Appeal allows tissue typing for human embryos under strict conditions* http://www.hfea.gov.uk/forMedia/pressReleases.htm

Human Genetics Advisory Committee (1998) *HGAC First Annual Report* http://www.doh.gov.uk

Human Genetics Advisory Committee (2000) *Terms of Reference of the National Antenatal Subgroup* http://www.doh.gov.uk

Human Genetics Commission (2000) *Prenatal Genetic Testing: Report for Consultation* Advisory Committee on Genetic Testing

Human Genetics Commission *Agenda and Minutes* 13/6/2000, 27/7/2000, 12/1/2001, 16/2/2001, 3/12/2001, 19/4/2002, 8/7/2002, 23/10/2002 http://www.hgc.gov.uk/subgroups/genetic_testing

Hussain, R (1998) 'The Impact of Consanguinity and Inbreeding on Perinatal Mortality in Karachi, Pakistan' *Paediatric and Perinatal Epidemiology, 12, 270-382*

Hussain, R & Bittles, A H (1998a) 'The Prevalence and Demographic Characteristics of Consanguineous Marriages', *Pakistan' Journal of Biosocial Science, 30, 261-275*

Hutchesson, A C J, Bundey, S Preece, M A Hall, S K, Green, A (1998) 'A comparison of disease and gene frequencies of inborn errors of metabolism among different ethnic groups in the West Midlands, UK' *Journal of Medical Genetics*, 35, pp. 366-70

Ibrahim, I. A. (1997) *A Brief Illustrated Guide to Understanding Islam* (Houston: Darussalam)

Illich, I (1995) *Limits to Medicine: The Expropriation of Health* (London: Marion Boyars)

Indian Media Review (9/1/2002) *Trust the Yankees and their 'little informed' president to come up with it...* http://indianmediareview.com/

IPPF (1974) *Islam & Family Planning: A Faithful Translation Of The Arabic Edition Of The Proceedings Of The International Islamic Conference Held In Rabat (Morocco), December, 1971 Vol. II* (Beirut: International Planned Parenthood Federation)

Iqbal, S. (1997) *Why are marriages still arranged by parents?* (Unpublished research paper)

Jameson, F (1991) *Postmodernism or, The Cultural Logic of Late Capitalism* (London: Verso)

Jaroka, L '*The (*Con)temporary Identity: Gypsies working in the movie "Sitiprinc"' *Identity and/in Movement, a postgraduate conference,* University of Hull

Jenks, C (1993) *Culture* (London: Routledge)

Kahneman, D & Tversky, A. (1984) 'Choices, Values and Frames', *American Psychologist* April, pp 341-350

Karlsen, S. & Nazroo, J. Y. (2000) 'Identity and structure: rethinking ethnic inequalities in health' Saffron and James Y. pp 38-57 in Graham, H. (Ed.) (2000) *Understanding Health Inequalities* (Buckingham: Open University Press)

Kerby, A (1991) *Narrative and the Self* (Bloomington: Indiana University Press)

Kevles, D J (1999) 'Eugenics and Human Rights' *British Medical Journal*, Vol. 319, 14 August, pp. 435-38

Knott, K 'The religions of South Asian communities in Britain', in Hinnells, JR (Ed) (1997) *A New Handbook of Living Religions* (Harmondsworth: Penguin)

Kwiatkowski, D. (2002) *Malaria versus the Human Genome* (http://www.wellcome.ac.uk/malaria/MalariaAndPeople/hbhgen1.html)

Lancet, The (1999) '*Molecular Medicine*', *The Lancet*, 354 (suppl 1): 1-37

Latour, B. in Law, J & Hassard, J (Ed) (1999) *Actor Network Theory and After* (Oxford: Blackwell Publishing)

Law, I. (1996) *Racism, Ethnicity and Social Policy* (London: Prentice Hall)

Law, J. in Law, J & Hassard, J (Ed) (1999) *Actor Network Theory and After* (Oxford: Blackwell Publishing)

Lawless, R I (1995) *Teesside's Muslims: their migration histories, settlement patterns and community development* (Middlesbrough: Cleveland County Council)

Layton, R (1997) *An introduction to theory in anthropology* (Cambridge: University Press)

Leach, E.R. (1961) *Pul Eliya: A village in Ceylon, a study of land tenure and Kinship* (Cambridge: Cambridge University Press)

Leach, E. R. (Ed) (1971) *Aspects of Caste In South India, Ceylon And North-West Pakistan* (Cambridge: Cambridge University Press)

Lee-Treweek, G & Linkogle, S. (Ed) (2000) *Danger in the Field: Risk and Ethics in Social Research* (London: Routledge)

Lenaghan, J (1998) *Brave New NHS? The Impact of the New genetics on the Health Service* (London: Institute of Public Policy Research)

Lewis, P (1994) 'Being Muslim and Being British: the Dynamics of Islamic Reconstruction in Bradford' in Ballard, R et al (1994) *Desh Pardesh, the South Asian presence in Britain* (London: Hurst & Co) pp. 58-87

Ley, P. (1988) *Communicating With Patients: Improving Communication, Satisfaction And Compliance* (London: Chapman & Hall)

Lindisfarne, N et al (2002) 'Reproducing the Multicultural Nation', *Anthropology Today* vol. 18, no. 4, 20

Lupton, D. (1994) *Medicine as culture: illness, disease and the body in western societies* (London: Sage)

McAvoy, B. R. & Donaldson, L. J. (1990) *Health Care for Asians* (Oxford: Oxford University Press)

McKeigue, P. 'Approaches to identifying genes that underlie ethnic differences in disease risk.' *Symposium on Health & Ethnicity,* Oxford Brookes, 16-17 April 1998.

McKie, R (2000a) *Ape Man: The Story of Human Evolution* (London: BBC Worldwide Ltd)

McKie, R (2000b) *Ape Man: Adventures in Human Evolution* (BBC/Learning Channel, transmitted February 2000)

Macpherson, W (1999) *The Stephen Lawrence Inquiry: Report of an Enquiry* (London: Home Office)

McLoughlin, S & Kalra, V S (1999) 'Wish you were(n't) here? Discrepant Representations of Mirpur in Narratives of Migration, Diaspora and Tourism', in Kaur R & Hutnyk, J

(Ed.) (1999) *Travel Worlds, journeys in Contemporary Cultural Politics* (London: Zen Books) pp. 120-36

McLuhan, M. & Fiore, Q. (1968) *The Medium is the Massage* (Harmondsworth: Penguin)

Maan, B (1992) The *New Scots, The Story of Asians in Scotland* (Edinburgh: John Donald Publishers Ltd.)

Madhok, R, Hameed, A Bhopal, R (1998) 'Satisfaction with Health Services Among the Pakistani Population in Middlesbrough, England', *Journal of Public Health Medicine* Vol. 20, No. 3, 295-301

Malik, F. M. (2000) 'Islamic And European Values Similarities And Differences', pp 96-105 in Cauquelin, J. et al (Ed) (2000) *Asian Values An Encounter with Diversity* (Richmond: Curzon)

Malik, J (1998) Making Sense of Islamic Fundamentalism *ISIM Newsletter* 1, 98, 27

Mange, E J Mange, A P (1993) *Basic Human Genetics* (Sunderland: Sinauer Associates)

Mange, E J Mange, A P (1999) *Basic Human Genetics, 2nd Ed.* (Sunderland: Sinauer Associates)

Marsh, B. (22/3/2004) *Taxpayer to fund 'designer baby' bid to save sick child* (London: Daily Mail)

Martineau, A White, M (1998) 'What's Not in a Name. The accuracy of using names to ascribe religious and geographical origin in a British Population', *Journal of epidemiology and Community Health*, 52, pp. 336-7

Medline (2004) http://www.nlm.nih.gov/medlineplus

Merry, S E (1997) 'Law, culture and cultural appropriation', *Yale Journal of Law and the Humanities* cited in Wright (1998)

Milburn, A (2000) *New and Improved Screening Services Announced* http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleaseNotices/

Modell, M & Modell, B (1990) 'Genetic Screening for Ethnic Minorities', *British Medical Journal* 200, 1702-1704

Modell, B & Kuliev, A M (1992a) 'Social and genetic Implications of Customary Consanguineous Marriage Among British Pakistanis', *Galton Institute, Occasional Papers, Second Series* (4)

Modell, B & Modell, M (Eds.) (1992b) *Towards a Healthy Baby: Congenital Disorders and the New Genetics in Primary Care* (Oxford: Oxford University Press) pp. 114-124

Modell, B Petrou, M (1994) 'Thalassaemia Screening: Ethics and Practice', in Cruckshank J K & Beevers, D G (Ed.) (1994) *Ethnic Factors in Health and Disease* (Oxford: Butterworth Heinemann) pp. 114-122

Modell, B & Anionwu, E N (1996) 'Guidelines for Screening for Haemoglobin disorders', in *NHS Centre for Reviews and Dissemination, Social Policy Research Unit* (York: York Publishing Services)

Modell, B et al (1997) 'Audit of prenatal diagnosis for haemoglobin disorders in the United Kingdom: the first 20 years', *British Medical Journal*, Vol. 315, 27 September, pp. 779-84

Modell, M et al (1998) 'A Multidisciplinary Approach for Improving Services in Primary Care: randomised controlled trial of screening for the haemoglobinopathies' *British Medical Journal*, vol.317, 19/9/1998

Modell, M (1999) *A Randomised Controlled Trial of the Effect of the Practice Based Genetic Screening Facilitator* (Department of Health) http://www.doh.gov.uk

Modell, B et al (2000) 'Informed Choice in Genetic Screening for Thalassaemia During Pregnancy: Audit from a national Confidential Enquiry', *British Medical Journal*, vol. 320, 337-341

Moser & Law in Law, J. (1999) *Good Passages, Bad Passages* in Law, J & Hassard, J (Ed) (1999) *Actor Network Theory and After* (Oxford: Blackwell Publishing)

Mull & Mull (1990) 'The Anthropologist in PHC' pp 304 in Coreil, J & Mull, J.D. (1990) *Anthropology and Primary Health Care* (Boulder: Westview Press)

Murphy, R (1996) *The Real and the Idea: A Study of the Effects of Ironstone Mine Closures on the Communities of East Cleveland 1946-1964* (University of Teesside: Unpublished MA Thesis)

Murray, U. (1998) *They Look After Their Own Don't They? Inspection of Community Care Services for Black and Ethnic Minority Older People* (London: Department of Health) http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsInspection

Musallam, B.F. (1983) *Sex and society in Islam Birth control before the nineteenth century* (Cambridge: University Press Cambridge)

Nazroo, J. Y. (1997) *The Health of Britain's Ethnic Minorities: findings from a national survey* (London: Policy Studies Institute)

Niccol, A. (Dir) (1997) *Gattaca* (Columbia TriStar Pictures)

Nielsen, J. (04/12/2003) *Racist backlash and Islamophobia after September 11th – the UK Record* unpublished paper, given at Dept. Social Anthropology, University of St Andrews

Nettleton, S (1995) *The Sociology of Health and Illness* (Cambridge: Polity Press)

Oakley, A. (1984) *The Captured Womb* (Oxford: Basil Blackwell)

Okasha, S (2002) *Philosophy of Science* (Oxford: Oxford University Press)

Old, J M et al (1986) 'First Trimester fatal Diagnosis for haemoglobinopathies: Report on 200 Cases', *Lancet,* 2, pp. 763-766

Oliver, M (1990) *The Politics of Disablement* (Basingstoke: Macmillan)

Orwell, G. (1954) *1984* (Harmondsworth: Penguin)

Panter-Brick, C (1991) 'Parental Responses to Consanguinity and Genetic Disease in Saudi Arabia', *Social Science Medicine, Vol. 33, No. 11, pp. 1295-1302*

Panter-Brick, C (1997) 'Coping with an Affected Birth: Genetic Counselling in Saudi Arabia', *Journal of Child Neurology,* Vol. 7, Supplement

Parry, O. & Pill, R. (1994) ""I don't tell him how to live his life": The doctor/patient encounter as an educational context' in Bloor, M & Taraborrellia, P. (Ed.)(1994) *Qualitative Studies in Health and Medicine* (Aldershot: Avebury)

Parsons, A. et al (1994) 'They must have got it wrong': The experiences of families identified by a newborn screening programme for Duchenne muscular dystrophy', in Bloor, M & Taraborrellia, P. (Ed.)(1994) *Qualitative Studies in Health and Medicine* (Aldershot: Avebury)

Pearson, M (1994) 'Sociology of Race and Health', in Cruckshank J K & Beevers, D G (Ed.) (1994) *Ethnic Factors in Health and Disease* (Oxford: Butterworth Heinemann)

Pelto, P. J. & Pelto, G. H. (1978) *Anthropological Research: The Structure of Inquiry* (Cambridge: Cambridge University Press)

Pembrey, M (1996) 'The New Genetics: a User's Guide', in Marteau, T. & Richards, M. (1996) *The Troubled Helix: social and psychological implications of the new human genetics* (Cambridge: Cambridge University Press)

Petrou, M et al (1990) 'Antenatal Diagnosis. How to Deliver a Comprehensive Service in the United Kingdom', *Annals of the New York Academy of Science*, 612, 251-263

Petrou, M & Modell, B (1996) 'Prenatal Screening for Haemoglobin', Disorders *Prenatal Diagnosis,* 15(13), pp. 1275-1292

Petrou, M et al l (2000) 'Long Term Effect of Prospective Detection of High Genetic Risk on Couples' reproductive life: data for Thalassaemia', *Prenatal Diagnosis*, 20(6), 469-274

Pfeffer, N (1998) 'Theories of Race, Ethnicity and Culture', *British Medical Journal,* Vol. 317, 14 November, pp. 1381-4

Pollitt, C. (1993) *Managerialism and the Public Services 2nd Ed* (Oxford: Blackwell)

Porter, D & Porter, R. (1989) *Patient's Progress Doctors and Doctoring in*

Eighteenth-century England (London: Polity Press)

Porter, R. (1997) *The Greatest Benefit to Mankind: a medical history of humanity from antiquity to the present* (London: Harper Collins)

Proctor, S R & Smith, I J (1992) 'A Reconsideration of the Factors Affecting Birth Outcome in Pakistani Muslim Families in Britain', *Midwifery*, 8, pp. 76-81

Qureshi, B. (1990) 'Alternative/Complimentary Medicine', in McAvoy, B. R. & Donaldson, L. J. (1990) *Health Care for Asians* (Oxford: Oxford University Press)

Rapp, R (1998) 'Chromosomes and Communication: The Discourse of Genetic Counselling', *Medical Anthropology Quarterly*, 2 (2), pp. 143-157

Rapport, N & Overing, J (2000) *Social and Cultural Anthropology* (London: Routledge)

Ratip, S et al (1995a) 'Psychological and Sociological aspects of the Thalassaemias', *Seminars in Haematology* 33(1), 53-65

Ratip, S et al (1995b) 'Psychosocial and Clinical Burden of Thalassaemia Intermedia and its Implications for Prenatal Diagnosis', *Archives of Disease in Childhood*, 72, pp. 408-412

Rauf, A (1998) *'Mirpuris'* Unpublished Research Paper

Redcar & Cleveland BC (1998) *Redcar and Cleveland 1997 Housing Needs Survey, Final Report March 1998: Vol. 1: Data analysis and discussion* (Durham: Northern Consortium of Housing Authorities)

Redcar and Cleveland B. C. *Racist Incidents and Hate Crimes* http://www.redcar-cleveland.gov.uk/YrCouncl.nsf'Web+Full+List/14B2878582F656

Redcar & Cleveland Partnership (2003) *Living in Harmony* (Redcar: RCVDA)

Redfield, R. (1960) *The Little Community, and Peasant Society and Culture* (Chicago: Chicago University Press)

Register of Electors, 16/2/1999 to 15/2/2000 South Bank JA, JB, JC, JD, JE (South Bank: Redcar & Cleveland BC)

Richards, M. & Marteau, T. (1996) *The Troubled Helix: social and psychological implications of the new human genetics* (Cambridge: Cambridge University Press)

Richards, T. 'The Genomic Challenge', *British Medical Journal,* vol. 318, 6/2/1999, pp241-2

Ritzer, G (1992) *The McDonaldization of Society: an investigation into the changing character of contemporary social life* (London: Pine Forge Press)

Rizvi, S.A.H et al (1999) 'Religious Circumcision: a Muslim View' *BJU International 83, Suppl. 1, 13-16*

Robertson, S & Savulescu, J (2001) 'Is there a case in favour of predictive genetic testing in young children?', *Bioethics* Vol. 15, no. 1, 26-49

Robinson, V (1986) *Transients, settlers and refugees: Asians in Britain* (Oxford: Clarendon Press)

Robinson, V (1990) 'Boom and Gloom: the success and failure of South Asians in Britain', in Clarke, C Peach, C Vertovec, S (Ed.) (1990) *South Asians Overseas, Migration and Ethnicity* (Cambridge: Cambridge University Press)

Royal College of Obstetricians and Gynaecologists (1996) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales* (London: RCOG)

Runnymede Trust (1997) *The nature of Islamophobia* http://runnymedetrust.org/meb/islamophobia/nature.html

Sargent, CF & Johnson, TM (Ed) (1996) *Medical Anthropology: Contemporary Theory and Method Revised Edition* (Praeger: Westport)

Schaffner, K. F. 'Philosophy of Medicine', in Salmon, M. H. et al (1992) *Introduction to the Philosophy Of Science* (Indianapolis: Hackett Publishing Company) pp 310-13

Schneider, D. M. (1984) *A Critique of the Study of Kinship* (Ann Arbor: University of Michigan Press)

Scott, R. (Dir) (1991) *Blade Runner (Director's Cut)* (Warner Bros Home Entertainment)

Seidel, G (1985) 'Culture, nation and "race" in the British and French New Right', in Levitas,

R (ed) *The Ideology of the New Right* (Oxford: Polity)

Seller, M. *Birth Research News Letter* Jan/Feb 1997 vol.2, no 1.

Shamsuddin, S. M. M. (1974) 'Birth Control – its lawfulness and methods', in IPPF (1974) *Islam & Family Planning: A Faithful Translation Of The Arabic Edition Of The Proceedings Of The International Islamic Conference Held In Rabat (Morocco), December, 1971 Vol. II* (Beirut: International Planned Parenthood Federation)

Shaw, A. (1988) *A Pakistani Community in Britain* (Oxford: Basil Blackwell)

Shaw, A (1989) *Getting By in Hindi & Urdu* (London: BBC Books)

Shaw, A (1994) '*The Pakistani Community in Oxford*' in Ballard, R et al (1994) *Desh Pardesh, the South Asian presence in Britain* (London: Hurst & Co) pp. 35-57

Shaw, A. (2000a) 'Conflicting Models Of Risk': Clinical Genetics And British Pakistanis', in Caplan, P. (Ed)(2000) *Risk Revisited* (London: Pluto Press)

Shaw, A (2000b) *Kinship and Continuity: Pakistani families in Britain* (Amsterdam: Harwood Academic Publishers)

Shaw, A. (2001) 'Kinship, Cultural Preference and Immigration: consanguineous marriage among British Pakistanis' *Royal Anthropological Institute, 7, 315-334*

Shaw, A. (2002) *'Why might young Muslims support the Taliban'*, Anthropology *Today* vol. 18, no. 1 pp5-8

Shaw, A. (2003) 'Interpreting Images: Diagnostic Skill in the Genetic Clinic', *Journal of the Royal Anthropological Institute*, 9, 1, pp39-55

Sillars, J (29/10/2002) 'Islamophobia will leave nowhere safe', *The Sun*, pp. 8

Sillence, P. (2002) 'The Medium is the Message: a discussion of South Asian women's access to health care during pregnancy, in a Northern English town' unpublished research document

Simpson, B et al (2002) 'Ethics on the Web: A Brief Guide to Resources', in *Anthropology in Action* vol. 9, No. 3, pp 49-53

Sinha, G. et al (1997) 'Prevalence and type of cerebral palsy in a British ethnic community: the role of consanguinity', *Developmental Medical Child Neurology*, 39(4), April 1997: 259-62.

Solomos, J. (1993) *Race and racism in Britain* (Basingstoke: Macmillan)

Solston, J (2000) *The Royal Institution Children's Lectures* (London: Channel 5)

Smith, R. (Ed) (1992) *Audit in Action* (London: British Medical Journal)

Stacey, M (1990) *The Sociology of Health and Healing* (London: Routledge)

Stanford University (2001a) *Chorionic Villus Sampling (CVS)*

http://stanford.edu/~holbrook/CVS.html

Stanford University (2001b) *Cystic Fibrosis Screening*

http://stanford.edu/~holbrook/CF_Info.html

Stanford University (2001c) *Expanded – Alphafetoprotein Screening test (X-AFP)*

http://stanford.edu/~holbrook/X-AFP.html

Stanford University (2001d) *Prenatal Ultrasound*

http://stanford.edu/~holbrook/ultrasound.html

Stanford University (2001e) *Amniocentesis*

http://stanford.edu/~holbrook/Amniocentesis.html

Steinberg, D L (1996) 'Languages of Risk: genetic encryption's of the female body', *Women: a Cultural Review* 7, 259-70

Strathern, M (1992) *Reproducing the future: essays on anthropology, kinship and the new reproductive technologies* (Manchester: Manchester University Press)

Strathern, M et al (2000) *Audit Cultures* (London: Routledge)

Strauss, A. & Corbin, J (Ed) (1997) *Grounded Theory in Practice* (Thousand Oaks: Sage Publications)

Strauss, A. & Corbin, J (1998) *Basics of Qualitative Research, 2nd Ed* (Thousand Oaks: Sage Publications)

Sun, The (09/03/2004) *Shame Again* page 6 and Editor's comments

Tassano, F (1995) *The Power of Life and Death: a critique of medical tyranny* (London: Duckworth)

The National Plus *BBC Condemned After Central Mosque Attack* (The Nation Group of Publications Pvt Limited) http://www.nation.com.pk/report/uk-com/page7.htm

The Times (29/11/2002) *No Racism: the British are xenophobes says foreign secretary*

The Times (17/01/2004) *Academics savage the return of Sambo*

Tidmarsh, E. in Chanarin, I. et al (1980) *Blood and its Diseases 2nd Ed.* (Edinburgh Churchill Livingstone)

Townsend, P. & Davidson, N. (Ed) (1982) *Inequalities in health: the Black report / Sir Douglas Black [et al.]* (Harmondsworth: Penguin)

Trades Union Congress (1996) *Black and Betrayed* (London: TUC)

Turner, B. S. (1991) 'Recent Developments in the Theory of the Body', in Featherstone, M et al (Ed) (1991) *The Body: Social Processes and Cultural Theory* (London: Sage Publications)

Turner, B. S. (1992) *Regulating Bodies* (London: Routledge)

Turner B S (1995) *Medical Power and Social Knowledge, 2nd Ed* (London: Sage Publications)

Turner, T (1993) 'Anthropology and Multiculturalism: What is anthropology that multiculturalists should be mindful of it?;, *Cultural Anthropology 8(4), 411-29*

Tyler, S A (1987) *The Unspeakable: Discourse, Dialogue and Rhetoric in the Post-modern World* (Madison: University of Wisconsin Pres)

Uberoi, P (1994) *Family, Kinship and Marriage in India* (Delhi: Oxford University Press)

UKTS (United Kingdom Thalassaemia Society) (2004) http://www.ukts.org/

Van den Berghe P L (1983) Human inbreeding avoidance: Culture in Nature *The Behavioural and Brain Sciences*, vol. 1, pp 91-102, 117-121

Veatch, R. M. (1999) 'Abandoning Informed Consent', in Kuhse, H. & Singer, P. (1999) *Bioethics: an anthology* (London: Blackwell), pp 523-32

Vertovec, S (1996) 'Multiculturalism, Culturalism, and Public Incorporation', *Ethnic and Racial Studies.* 19 (1): 49-69

Viscusi, W.K. (1998) Rational Risk Policy: The 1996 Arne Ryde Memorial Lectures (Oxford: Clarendon Press)

Wade, P. (1992) *Race and Ethnicity in Latin America* (London: Pluto Press)

Wade, P. (2002) *Race, Nature and Culture* (London: Pluto Press)

Wellcome News 'From Genome to Health', *Wellcome News*, 20, Q3 1999

Wellcome News 'Malaria: the next 100 years', *Wellcome News*, 21, Q4 1999

Wellcome News 'HFEA relaxes policy on embryo screening for tissue typing', http://www.wellcome.ac.uk/en/genome/geneticsandsociety/hg15n027.html

Werbner, P (1990) 'Manchester Pakistanis: division and unity', in Clarke, C Peach, C Vertovec, S (Ed.) (1990) *South Asians Overseas, Migration and Ethnicity* (Cambridge: Cambridge University Press)

Werbner, P. (1996) 'Stamping the Earth with the Name of Allah: *Zikr* and the Sacralizing of Space Among British Muslims' *Cultural Anthropology, 11 (3), 309-38*

Werbner, P. (1999) 'Global Pathways. Working Class Cosmopolitans and the Creation of Transnational Ethnic Worlds' *Social Anthropology*, 7, 1, 17-35

Weatherall, D. J. (1985) *The New Genetics and Clinical Practice, 2nd Ed* (Oxford: Oxford University Press)

Weatherall, D. J. (1998) 'Inherited Disorders of Haemoglobin', *Symposium on Health & Ethnicity,* Oxford Brookes, 16-17 April 1998.)

Wilkie, A (2000) 'Genetics and Society', Lecture, 4 September, *Wellcome Postgraduate Research Seminar,* Hinxton, 4-7 September 2000

Wilkie, T. (1998) 'Navigating the Moral Maze: the biomedical ethics programme', in *Wellcome Trust News*, 1998, Q1, pp 8-9

Williams, C et al (2004) 'Can antenatal counselling be nondirective?', *Wellcome Trust News* (38, Q1, 2004) http://www.wellcome.ac.uk/en/genome/geneticsandsociety/hg14f008.html

Wright, S (1998) 'Politicisation of Culture', *Anthropology in Action*, Vol. 5, No. ½

Yahya, H. (2001) *The Evolutionary Deceit* (Istanbul: Kultur Publishing)